

**SELF-PERCEIVED IMPACT OF A COMMUNITY-BASED
REHABILITATION PROGRAMME IN TANZANIA ON
QUALITY OF LIFE OF CHILDREN WITH CEREBRAL
PALSY AND THEIR CARERS**

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Definition of terms

Impairment can be physical, mental or intellectual; it refers to total or partial loss of a body function or part of the body structure (WHO, 2001).

Disability is the loss or limitation of opportunities that prevent people who have impairments from taking part in the normal life of the community on an equal level with others, due to physical and social barriers (Finkelstein & French, 1993).

Cerebral palsy "is a disorder of movement and posture due to congenital malformation or an acquired lesion of the immature brain. The lesion affects the immature brain and interferes with the maturation of the CNS. The malformation can occur before, during or after birth, and is sometimes the result of a disease in early childhood"

(Wolf-Vereecken, 1993: p. 43).

Intellectual disability is described by a number of terms with varying levels of acceptability across organisations and professions. WHO's International Classification of Diseases (ICD-10) (1996) still uses the term 'mental retardation', although it is recognised that some groups of professionals have serious reservations in using this term. In this study the term 'intellectual disability' has been used since it has the highest extent of acceptability among organisations of people with disabilities.

Mental retardation is a condition of arrested or incomplete development of the mind characterised by impairment of skills and overall intelligence in areas such as cognition, language, and motor and social abilities. Also referred to as intellectual disability or handicap, mental retardation can occur with or without any other physical or mental disorders (WHO, 2001b: p. 3). Adaptive behaviour is always impaired, but in protected social environments where support is available this impairment may not be at all obvious in subjects with mild mental retardation (WHO, 1996).

Community-based rehabilitation workers (CRWs) operate within their local community with people with disabilities, their families and the local community.

Their role is to identify people with disabilities in the community, carry out assessment and treatment in the community, raise awareness, network with local resources, and promote local services which are accessible and inclusive.

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Abstract

There is no real agreement on how to evaluate community-based rehabilitation (CBR) programmes. Many diverse methods have been used. This qualitative evaluation study aimed to describe the change in quality of life of children with cerebral palsy and their carers as perceived by the carers themselves and some of the children. The study was conducted at the ART CBR programme that operates in the city of Dar es Salaam in Tanzania.

Individual in-depth interviews using an interview guide were conducted with 21 carers of children with cerebral palsy. Two children who were over the age of 10 and were able to communicate were interviewed separately.

The findings showed that physical exercises - the main service offered by the programme - are valued as extremely important by carers. The programme facilitates improvement in physical function, but for most children did not bring about a cure. Equipment was not always appropriate for the child and was insufficiently available. Carers believed that education was very important. While some children were able to attend school, not all have access to quality education and more could be done to make schools more inclusive.

Carers identified emotional and spiritual support as areas in which more could be done. Carers also expressed a lack of confidence in their ability to bring up their child, and felt that more professional input was required, particularly for carers of more severely disabled children.

Overall, the findings demonstrate that the quality of life of disabled children and their carers had improved as regards physical well-being and right to education, but more input is still required to address emotional and spiritual well-being.

Acknowledgements

First of all I need to thank the children and the carers, without whom this evaluation would not have been possible. Their stories inspired me and convinced me once again of the importance of continuing development of CBR programmes. There is, however, still a long road to travel.

I owe particular thanks to Mr Geert Vanneste, CEO of Comprehensive Community-Based Rehabilitation Tanzania, who gave me the opportunity to do this evaluation and who allowed me to use part of the findings for my dissertation. More than 10 years ago he introduced me to the management of CBR programmes and supported the notion that we needed more than quantitative data to show the impact of CBR.

I would also like to acknowledge the assistance of colleagues at the ART CBR and Kilimanjaro CBR programmes. I would like to give particular thanks to Mrs Joyse Mallya, Programme Manager, Kilimanjaro CBR, for having been such a great friend and for her support over the past years. I am grateful to Mr Arbogast Kajuna and the ART CBR staff for welcoming me into their programme and giving me their full support and cooperation despite their already busy schedules. I am especially grateful to Egline Chibeu for her tireless efforts in transcribing and translating the interviews.

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CHAPTER 1

Introduction

1.1 Background to the study

Community-based rehabilitation (CBR) has been promoted as the most appropriate model of service delivery for people with disabilities (PWDs) in developing countries (Wirz & Thomas, 2002). Since disablement means many things to different people, rehabilitation services have evolved differently in varying contexts. Disability is "the loss or limitation of opportunity that prevents people who have impairments from taking part in the normal life of the community on an equal level with others due to physical and social barriers" (Finkelstein & French, 1993: p. 27). Examination of this definition clearly demonstrates that it is not just the impairment that creates problems, but the manner in which various environments exclude PWDs.

The CBR approach attempts to address these issues. CBR has been described by Helander as "a strategy for *enhancing the quality of life of disabled people* by improving service delivery, by providing more equitable opportunities and by promoting and protecting their human rights" (1993, p.8).

Rehabilitation outcomes are influenced by many factors, such as social, familial and personal factors as well as poverty (Boyce, Broers & Paterson, 2001). This results in challenges in terms of evaluation of CBR; currently there is no real agreement about evaluation methods and many diverse methods have been used (Wirz & Thomas, 2002). Many evaluations are never published and remain buried on the bookshelves of programmes.

In Tanzania there are no Government CBR programmes, but there are several CBR programmes around the country that are run by non-governmental organisations (NGOs). There is a lack of information about all of the existing programmes.

CCBRT (Comprehensive Community-Based Rehabilitation Tanzania) is an NGO which runs several disability-related programmes, including a hospital, an HIV/AIDS programme and two CBR programmes, one in Dar es Salaam and one in the Kilimanjaro region.

1.1.1 Tanzania

The United Republic of Tanzania has boundaries with Kenya, Uganda, Rwanda, Burundi, Zambia, Malawi, Mozambique and the Indian Ocean. It came into existence in 1964 after independence from Britain through political union of Tanganyika and the islands of Zanzibar (Unguja and Pemba). Zanzibar retains considerable autonomy of its internal affairs, having semi-autonomous status.

According to the 2002 Census, Tanzania has a population of 34 443 603 (National Bureau of Statistics, 2002). The country is one of the poorest in the world, and was ranked 140 out of 162 on the 2001 United Nations Development Program Human Development Index, where the four indicators of longevity, educational attainment, standard of living and adult literacy were used (UNDP, 2001). Life expectancy was 50 years for men and 52.2 years for women. There is a net enrolment into education rate of 90.1% (Ministry of Education and Vocational Training, United Republic of Tanzania, 2005); however, together with Burundi, Tanzania has the lowest rate of transition from primary to secondary education, with only 20% of pupils enrolled in the last grade of primary education moving on to secondary education (UNESCO, 2006). The expectation is that this will rise to 28% in the coming 6 years ((UNESCO Institute of Statistics, 2006)). Most of the people (79%) still earn their livelihood from agriculture (International Labour Organisation (ILO), 2004).

Tanzania is a 'plural' society, with about 120 ethnic groups, most of whom have their own language. About 95% are Bantu. Nilotic pastoralists make up one minority group, and another is the small Asian group that has great economic power. Most people are fluent in Kiswahili with very few able to speak English - though both are official languages. About 40% of the population is Christian, one-third is Muslim and about 23% belong to traditional religions (ILO, 2004).

1.1.2 PWDs in Tanzania

During the 2002 Census data were collected on PWDs in Tanzania, but these are as yet unpublished. According to UNESCO only about 3% of PWDs in Tanzania received basic education (UNESCO, 2003).

Tanzania has no rehabilitation section in the Ministry of Health. There is no document or register that records activities and persons/organisations involved in the field of rehabilitation in general or in CBR specifically.

1.1.3 CBR in Tanzania – the ART CBR programme

CCBRT is a private NGO registered under the Tanzanian Societies Act, No. SO8261 on 12 October 1994. CCBRT was established in Dar es Salaam with the goal of contributing towards poverty alleviation by responding to the lack of accessible and affordable services for disabled people in Tanzania, who are among the poorest of the poor.

A survey carried out by CCBRT in 1994-1995 highlighted an extreme shortage of preventative, curative and rehabilitation services for PWDs, in addition to HIV/AIDS patients and orphaned children.

ART CBR is a programme of CCBRT based in Dar es Salaam. It provides services in three districts of Dar es Salaam which together have a total population of 2 497 940 (National Bureau of Statistics, 2002).

The overall aim of ART CBR is to improve the quality of life of disabled children and their families. Community rehabilitation workers (CRWs) operate in the homes and local communities of approximately 1000 disabled people, and network with other services. The programme has the following main objectives:

- Prevention of disabilities by finding and referring people with operable impairments and treatable medical conditions such as cataracts, clubfeet and epilepsy;
- To provide individual rehabilitation to children below the age of 16 years with disabilities and their families; and
- To work with PWDs in their local communities at community centres and in their homes.

Collaboration with other existing services is of crucial importance for a CBR programme. CRWs and physiotherapists refer PWDs to available services such as educational services, health services (those not offered by CCBRT), vocational training, income generating projects, etc.

The programme works mainly with children aged 0 – 15 years who have a variety of impairments such as physical impairments (cerebral palsy, spina bifida), multiple disabilities, epilepsy and deafness.

The CBR programme works within a context in which poverty is part of everyday life for most people. A major problem for the programme remains the lack of 'community' in Dar es Salaam, which is, like many African cities, rapidly expanding, attracting people

from all around the country. Consequently, persons with disabilities and their problems are rarely a priority for investment or for government efforts. According to a British Government Department for International Development workshop (DFID, 2005), the Tanzanian national health budget of 2001 granted \$12 per person for public health.

1.2 This study: Evaluation of ART CBR, Dar es Salaam

The management of CCBRT requested that the researcher conduct an evaluation of its CBR programmes. (The CBR programme in Dar es Salaam started in 1994) Although there is a plethora of output data available, the programme has not systematically collected or analysed any information concerning impact on the quality of life of PWDs. CCBRT decided to evaluate the perceptions of participants in the CBR programme with regard to the programme activities and how these have influenced the quality of their lives.

Since CBR programmes are highly dependent on external funding from other organisations, it is important to secure this support as there is only limited support from government. One mechanism to secure future support is to present evaluation results showing impact of the programmes' activities to potential funding organisations.

An impact study is an effective way of evaluating programmes; it can provide information concerning strong and weak points, and make recommendations for improvements as well as strategies to achieve them.

It was strongly felt that this input should come to a large extent from the PWDs themselves, by using an evaluation method which gives the beneficiaries of CBR a voice. An impact study was carried out in the Kilimanjaro CBR programme of CCBRT, which was used to inform the evaluation in the Dar es Salaam area.

The present study focuses on children with cerebral palsy and their carers, and is a limited qualitative study within the larger evaluation. The aim of the study was to examine how children with cerebral palsy and/or their carers perceived the change in their quality of life that resulted from their participation in the CBR programme in Dar es Salaam.

The researcher works in the Kilimanjaro CBR programme, but has never worked in the ART CBR programme. It is therefore assumed that the researcher had a neutral and objective position towards the ART CBR programme. The researcher has more than 10 years' experience in a similar programme in Tanzania.

1.2.1 Purpose

The purpose of the study was to evaluate, from the perspective of children with cerebral palsy and their carers, the effect of the ART CBR programme activities on the quality of their lives.

This study provided PWDs and their families an opportunity and voice to comment on which services and activities they found useful and how the programme could be improved. The evaluation will provide the staff with feedback from the PWDs themselves and their carers, enabling the staff and management to learn from their work and to incorporate suggested improvements into future programme planning and implementation.

1.2.2 Rationale

The ART CBR programme has about 10 years of field experience. A substantial amount of quantitative data is available with respect to the number of people served. The programme maintains progress reports on individual clients. There has not yet been a formal evaluation which can provide information on the effect of programme activities on quality of life of the people served. It was considered important to obtain this information from the clients themselves. Children with cerebral palsy are the programme's largest client group. The opinion of the PWDs themselves and their carers should inform the practice of the programme.

1.2.3 Significance

Very few studies have been published about the impact of CBR programmes. This study could be a useful resource if the results are shared and discussed with other CBR programmes. In this way it will assist in developing good practice, and provide information which will enable potential donors to make informed decisions.

By obtaining and addressing the opinions of the beneficiaries, the programme will also become more accountable to the PWDs and their carers that it serves (Save the Children, 2003).

1.2.4 Problem statement

Monitoring and evaluation of the ART CBR programme to date has focused on quantitative data. Although the programme has been operating for over 10 years, no qualitative evaluation has yet been conducted.

The ART CBR programme aims to improve quality of life of PWDs. Currently the programme does not know how the PWDs and their carers perceive the effects of the programme and any changes in their quality of life. There is also limited information in the literature about the evaluation of the self-perceived change in quality of life of PWDs participating in CBR programmes.

1.2.5 Aim of the study

To describe any change in the self-perceived quality of life of children with cerebral palsy and their carers who are involved in the ART CBR programme at CCBRT.

The core dimensions of quality of life which will be used are (WHOQoL, 1994; Schalock, 1996; WHO/Swedish Organisations of Disabled Persons International Aid Association (SHIA), 2002):

- Physical well-being/physical health;
- Emotional well-being/self-esteem/psychological state;
- Empowerment and influence;
- Self-reliance/independence/personal development;
- Social inclusion/social relationships; and
- Confidence and trust in society to fulfil its human rights obligations.

1.2.6 Main objectives

- ❑ To describe the effects of the rehabilitation programme on the different dimensions of quality of life of children with cerebral palsy.
- ❑ To describe the effect of the rehabilitation programme on the different dimensions of quality of life of the carers of the children with cerebral palsy.
- ❑ To describe the programme activities which have been perceived as being most beneficial in achieving a change in quality of life.

This study forms one component of a larger evaluation of the entire CBR programme, and will focus only on children with cerebral palsy and their carers.

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CHAPTER 2

Literature review

2.1 Introduction

CBR has been promoted as the most appropriate mechanism of assisting PWDs. Although there is overall agreement on the definition of CBR, it is interpreted differently. This has resulted in many ways of implementing CBR.

CBR aims to empower PWDs and build inclusive communities with the ultimate aim of improving quality of life. It is increasingly acknowledged that PWDs and their families should be active partners in CBR (Wirz & Thomas, 2002). It is therefore self-evident that as the main beneficiaries of CBR programme activities - the PWDs themselves - should be asked their opinion on the effect of the CBR programme activities on their quality of life.

Minimal research has been carried out on the effectiveness of CBR programmes. Mitchell (1999, p. 9) commented: "little quality research on CBR has been placed in the mainstream of scientific literature". There is no real agreement on nor established methodology to evaluate whether CBR programmes make a difference in the lives of PWDs. Wirz and Thomas (2002) state that too few evaluations of CBR programmes have been published, and that hardly any demonstrate the effectiveness of a CBR programme.

2.2 What is CBR, and how did it come about?

The CBR approach has been described as a strategy for enhancing the quality of life of disabled people by improving service delivery, providing more equitable opportunities, and promoting and protecting their human rights (Helander, 1993).

In 1994 three United Nations (UN) Organisations (ILO, UNESCO and WHO) published a 'joint position paper' and developed a definition of CBR (ILO *et al.*, 1994), which stated that: "Community-based rehabilitation (CBR) is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all PWDs. CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services".

In 2004 the organisations published a new Joint Position Paper to describe and support the concept of CBR as it was evolving, with its emphasis on human rights and its call for action against the poverty that affects many PWDs. CBR was described as "a strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities"(WHO, 2004, title page). This description adds poverty reduction, thereby acknowledging that many PWDs in developing countries live in poverty.

Rehabilitation is, however, not a new phenomenon in Africa. Miles (2003) states that many components of CBR were informally practised over previous centuries. There are records of self-help groups and PWDs seeking different treatments and descriptions of different appliances (Kisanji, 1995).

The concept of disability is not straightforward. It is a fluid concept and is understood very differently in different cultures. Many cultures in Africa do not have an overall concept of and terminology for PWDs. PWDs are grouped according to a specific impairment, such as "the blind" and "the deaf", and non-disabled people often have very different ways of responding to people with different impairments (Groce, 2001; Kisanji, 1995; Ingstad & Whyte, 1995). An impairment which in one environment creates problems might not be noticed at all and not be seen as a disability within a different environment (Groce, 2001, 1999; Helander, 1993).

Impairment and disability are not synonymous. Disability is created by negative attitudes, and the physical, cultural and social barriers which prevent people from participating in family and community life. Disability is the result of social exclusion and discrimination (Albert, McBride & Seddon, 2004; Barnes, 1999).

Attitudes towards PWDs in Africa are often portrayed as being negative. Ingstad (1990) argues that this is stereotyping of non-Western cultures, and that it is a recently created 'North-South myth' whereby, in order to raise money and create awareness, a negative picture of the situation for disabled people has been painted that emphasizes shame, hiding, killing, etc.

According to Kisanji (1995), proverbs provide evidence of a culture's understanding of both the unique features of given disabilities as well as the limitations associated with them. The proverbs present disability as permanent, and show that in Tanzania people are able to make a clear distinction between intellectual disability and mental illness. Kisanji concludes that although, as expected, there are elements of negative attitudes, the overall picture is one of tolerance, respect, care, assistance and integration.

CBR came about due to the realisation that institution- and centre-based rehabilitation could not address all the issues facing PWDs. In Western countries up until that time, rehabilitation had been very individual and medically oriented. It was focused on the problems of the individual and how the person could be normalised. It was realised that different barriers in the community and local environment caused a lot of the problems experienced by PWDs (WHO, 2004).

Up to this point rehabilitation services had not taken into account that environments can be enabling for PWDs but can also create barriers. Different models of rehabilitation or disability, such as the International Classification of Functioning, Disability and Health (ICF) and the Canadian model of human occupation, categorise environments differently, with the physical, cultural, social, economic and institutional environment (WHO, 2001a; Canadian Association of Occupational Therapists, 1997). Examples of environmental barriers are negative attitudes, physical terrain that is difficult for people with mobility impairments, schools which do not accept children with disabilities, health centres not able to offer appropriate support, etc. The environment has to become more inclusive for PWDs to be able to function and have a satisfactory quality life.

The CBR concept was developed by the WHO at the time when primary health care became popular and accepted as the best way of promoting health in developing countries (Walt & Vaughan, 1981). Closures of large institutions in Europe and North America were the norm, and mainstreaming became popular (Wolfensberger, 1980; 1985). In Africa generally, however, very few institutions existed - then or currently. Health services and especially so-called 'medical rehabilitation' services are insufficient in number or non-existent.

Although CBR was thought to have been initiated for developing countries, it did not emerge as an expressed need from developing countries. Finkenflügel (2004) presumes that CBR came to be the preferred approach promoted by the WHO due to the limited resources available for PWDs in developing countries and the presumed high number of PWDs in need of help. He continues to say that there is no documented opposition to institutions by rehabilitation workers or by PWDs.

The definition of CBR is very comprehensive and allows for different interpretations. Many different strategies were developed to achieve the stated objectives, and this is one of the reasons that there are so many different 'types' of CBR programmes and different ways of 'doing' CBR (Peat, 1997).

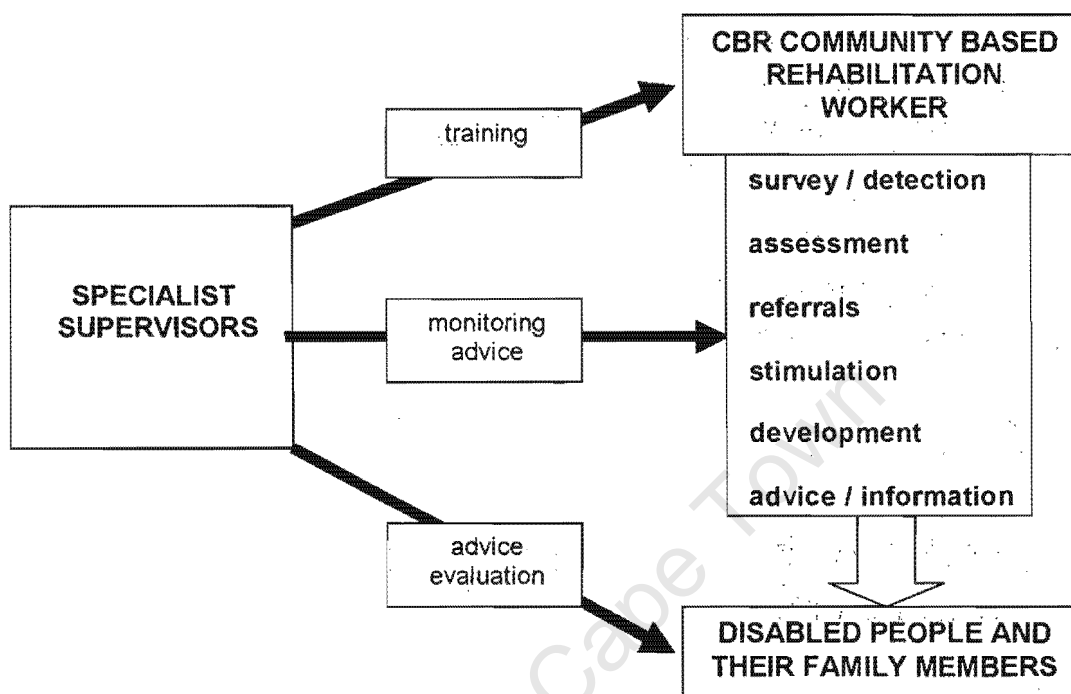
Poverty is a daily reality for a large part of the Tanzanian population. It has been estimated that over half the population live below the poverty line, defined in Tanzania as US\$ 0.65 per day per person. "As many as 40% live in abject poverty, that is, in a situation where their income is insufficient to buy food to cover minimum nutritional needs" (URT, 2001: p. 14). PWDs have been estimated to comprise 15-20% of the poor in developing countries (Elwan, 1999), and are often poorer than non-disabled persons. PWDs lack access to health care, rehabilitation, education, skills training and livelihood activities (DFID, 2000). Only 2% of PWDs in developing countries have access to basic services (DFID, 2000).

2.3 CBR strategies

One CBR strategy is to employ local community-based rehabilitation workers (CRWs) who assist PWDs within their local communities (see Figure 1). The CRWs meet the PWDs at their homes or in centres in the community. They work with PWDs, their families and with the local community. They might be supervised by rehabilitation specialists such as occupational therapists, physiotherapists, educationalists, and so on (Vanneste, 1997).

Figure 1 (Vanneste, 1997: p. 132)

THE ROLE OF THE DIFFERENT STAKEHOLDERS IN CBR



Working with a person within his or her own community means not only working with the individual but also with his or her family, the community and the environment in which this takes place.

After an initial assessment, an individual rehabilitation programme is developed together with the PWD and his/her family. They receive training on how to carry out the rehabilitation programme and how to integrate it within their daily life activities. Parents receive training on how to stimulate the development of their child, and they are supported in obtaining educational opportunities for their children (Helander, 1993). At the same time, the programme works on making community services more accessible and inclusive.

CBR is a complex process with many people involved. CBR is carried out in the community, which is an unstructured environment. A major challenge facing rehabilitation services worldwide is the need to measure the effects of CBR on the quality of life (Powell & Mercer, 2002). In developing countries there has been less

emphasis on evaluation than in the so-called developed world, although there is a great need to demonstrate effectiveness within the limited resource pool there.

2.4 Quality of life

Quality of life is a broad multidimensional construct which is influenced by cultural norms and expectations. To formulate a definition of quality of life, the WHO conducted an international study in more than 30 centres worldwide. The final definition adopted by the Quality of Life group is:

"An individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns. It is a broad-ranging concept, incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment" (WHO QoL Group, 1994, p. 43).

From the definition it can be seen that "quality of life has a multi-element structure consisting of different domains" (Petry, Maes & Vlaskamp, 2005, p. 35). Different people have made different conceptualisations and differ slightly in diversity, nature and elaboration of domains mentioned. Schalock *et al.* (2002) define eight quality of life dimensions: (i) emotional well-being, (ii) interpersonal relations, (iii) material well-being, (iv) personal development, (v) physical well-being, (vi) self-determination, (vii) social inclusion, and (viii) rights. In the model of Felce and Perry (1995, 1996a & b) five domains ((a) physical well-being, (b) material well-being, (c) social well-being, (d) development and activity, and (e) emotional well-being) are further divided into sub-domains (Felce & Perry, 1995, p. 53).

Quality of life is a key outcome of rehabilitation that determines the demand for service and influences the clients' compliance and satisfaction with treatment. The challenge lies now in measuring quality of life in its uniqueness to individuals (Carr & Higginson, 2001).

2.5 Evaluation research

Evaluation is the application of skills or the process to determine the worth, merit and value of a practice (McMillan & Schumacher, 2001; Vig & Kraft, 1994). "Three major reasons for conducting evaluation research are planning, improving and justifying (or

not justifying), procedures, programmes and/or products" (McMillan & Schumacher, 2001, p. 528). Evaluation can have a formative or summative purpose. Formative evaluation develops or improves the object being evaluated and summative evaluation examines the effect or outcome of an objective.

Formative evaluations are used to strengthen or improve a programme, for example they help to form it by examining the delivery of the programme, the quality of its implementation, and the organisational context, personnel procedures and inputs (Trochim, 2002). Summative evaluation describes what happens subsequent to the delivery of a programme, whether the object can be said to have caused the outcome; determining the overall impact of the causal factor beyond only the immediate target outcomes; and estimating the relative costs associated with the object (Trochim, 2002). Summative evaluation can be subdivided into outcome evaluations, impact evaluation, cost-effectiveness and cost-benefit analysis, secondary analysis and meta-analysis (Trochim, 2002).

Evaluation research can assist with decision making, programme development and design, programme quality and impact and potential for improvement (Bailey, 1997). What distinguishes evaluation research from other forms of social research is not the methods that evaluators employ, but the purpose to which the methods are put (Babbie, 1995). The primary purpose of evaluation is "not prove but to improve" (Stufflebeam & Shinfiedl, 1985, p. 151).

Challenges in evaluation research are not only the issues of validity, reliability and methodological rigor, but also the reputation of the evaluator and how the evaluation is positioned relative to the programmes' organisational structure (Simon & Christman, 2005). Evaluation research emanates from a formal contractual relationship between a client and the evaluator, with certain specified obligations and expectations. Normally it is the evaluation proposal that defines the terms of the relationship, including resources, timeline and budget (Simon & Christman, 2005).

Evaluator involvement in a programme is still being debated, and there are different views. Some call for very limited involvement and argue that for independent judgement, distance is required (Scriven, 1997). Others promote 'circumscribed collaboration' where evaluators consult with programme stakeholders to determine the focus and design of the evaluation; feedback about the evaluator's preliminary findings might also be sought (Patton, 1997; Research for Action, 2000). A third group promotes more participatory approaches and calls for deep involvement of the

evaluator in the setting; this might include teaching, mentoring, coaching and facilitating (Brown, 1996).

In developing countries few evaluations have been done, although there is a great need to maximise the effectiveness of services in the face of limited resources (Commission on Health Research for Development, 1990). Funding agencies, policy makers, programme implementers and user groups increasingly require evidence-based practice (Wirz & Thomas, 2002). What can a CBR programme learn from the people it serves? To what extent is the programme capable of changing quality of life?

2.5.1 Evaluation of CBR

Although it has been said that the field of CBR is 'evidence poor', i.e. lacking experimental studies, randomised controlled trials and systematic reviews, it has been recognised that it is also 'data rich' in the sense of having a wealth of evaluations, descriptive analysis and more subjective appraisals (Kuipers & Hartley, 2006). Evaluators need to use methodologies that are more refined to be able to use these evaluations for research. However, even if this is done, evaluations of CBR programmes are often concerned with the outcome of the rehabilitation process. These are often quantitative studies relating to the functional processes of PWDs and the number of people assisted, how often they were seen, and the cost of rehabilitation per client (Finkenflügel, 2004).

This type of evaluation typically will favour quick-fix approaches such as prevention of disabilities through operations on cataracts and clubfeet. More people can be seen and treated; therefore, there is a potentially lower cost per client.

It is important to provide evidence for managers, donors and other stakeholders that rehabilitation of PWDs is worthwhile and effective. As recipients and consumers of CBR the opinions of PWDs are essential to the provision of such information.

An important question is whether the evaluation should be "provider-" or "consumer-" based. In other words, should the evaluation be derived from an objective assessment by staff, or should it reflect 'subjective' perceptions of one's own disability? (Boyce, Broers, & Paterson, 2001). Evaluations based on the opinion of the beneficiaries have become more common, and often use some form of self-assessment of the perceived impact of an intervention.

Lundgren-Lindquist & Nordholm (1996) evaluated the impact of CBR in a Botswana village. In 1993 they reassessed 77 of 132 programme participants originally assessed

in 1990, comparing their activity of daily living skills. These data did not show any real differences. They also assessed the quality of life of the participants, using a retrospective judgement, asking: "*How is your life today compared to three years ago?*" (Lundgren-Lindquist & Nordhom, 1996: p. 520). Here quantitative data were collected, and it was suggested that there is a great need for qualitative evaluations.

The need for evidence-based CBR has been mentioned by Fransen (2005) and Peat (1997). CBR programmes and their activities need to be evaluated for their outcome, impact and effectiveness, but defining a measurable outcome is not easy. If a programme achieves its objectives, these may not be the outcomes that PWDs and their relatives value or expect.

The long-term objective of CBR is to improve the quality of life of PWDs. It is important to evaluate not only the programmes' objectives and outcomes, but also the changes resulting from the CBR programmes' activities in the lives of the PWDs.

2.5.2 Evaluating quality of life

Which measures can be used to find out how individuals within their unique contexts perceive and value their quality of life? There are many evaluation measures; however, most are developed for specific conditions or impairments (Cummins, 1997).

Only few quality of life documents are for use for a varied group of PWDs who have very different impairments. Most of those measures use questionnaires and attempt to quantify the data, aiming to collect objective data in order to make comparisons of individuals' circumstances. This differs from subjective measurement, in which individuals report on their perceptions of their circumstances (Fresher-Samways, Roush, Choi, Desrosiers & Steel, 2003).

Not everything can be captured by counting. "To fully grasp the meaning of a change in life for particular persons it is necessary to develop a description of life quality that integrates interdependent dimensions of quality into a whole that is placed in context" (Patton, 2002, p.150). Quality has to do with nuance, with making sense of your life and what you compare yourself to when you decide how well you are doing (Patton, 2002).

2.6 What is cerebral palsy?

Cerebral palsy is the number one cause of disability in children worldwide (Hinchcliffe, 2003). In developing countries little attention is given to these children, and few therapists are able to assist them (Hinchcliffe, 2003; Helander, 1993).

Cerebral palsy is a complex condition which presents differently in every child (Hinchcliffe, 2003). It is a syndrome of a number of motor disorders caused by damage to the brain and central nervous system during the growth and development phases. It produces disorders of movement or posture and is non-progressive, although the symptoms and signs may vary as the child matures (Hutton & Pharoah, 2006).

Cerebral palsy is defined both in terms of topographical distribution of the motor disorder (hemiplegia, diplegia, quadriplegia, etc.) and the presumed neuro-pathological site of the lesion, such as spasticity (cortex), dystonic/dyskinetic (basal ganglia), and ataxias (cerebellum) (Brown, 2003, p. 30).

During a study conducted in 1986 in Dar es Salaam it was found that the most common type of cerebral palsy was spastic quadriplegia (36%), followed by spastic diplegia (20%) and spastic hemiplegia (15%) (Karume & Mgone, 1990). In 70% of the children the cerebral palsy was associated with other severe impairments, of which the most common was epilepsy (35%), followed by deafness, speech disorders and blindness (Karume & Mgone, 1990).

Another study reported that about one-third of children with cerebral palsy are mildly intellectually impaired, one-third are moderately or severely impaired, and the remaining third are intellectually normal (NNDS, 2001). It was also found that intellectual impairment or mental retardation are more common among children with spastic quadriplegia.

Children with cerebral palsy have a varied level of functioning, from a single mild movement disorder to severe multiple impairments. While a child with severe cerebral palsy might be unable to walk and will need extensive, lifelong care, a child with mild cerebral palsy might only be slightly awkward and require no special assistance (NNDS, 2001).

The outcome of rehabilitation varies. Some children will achieve good function while others will remain very dependent. It has therefore been realised that studies of children with cerebral palsy should not just include impairment, but also their level of activity and participation and how this is influenced by their daily environmental context,

in order to be able to fully capture the complex inter-actional nature of the life experience of these children and their families (Rosenbaum & Stewart, 2004).

A lifestyle assessment score (LAS) has been developed to assess the impact of cerebral palsy on children and their families using a quantitative questionnaire (Mackie, Jessen & Jarvis, 1998). Although "severe disabilities are associated with higher LAS scores, half of those with severe disabilities have LAS scores of less than 70" (Hutton & Pharoah, 2006, p. 257). This means that their lifestyle is of higher quality than expected if the severity of their impairment is taken into consideration. Even though lifestyle is associated with quality of life, it is not identical to it.

2.6.1 Quality of life and cerebral palsy

Children with cerebral palsy have a reduced quality of life, but the quality is further reduced in children with more severe impairments (Petty, Maes & Vlaskamp, 2005). Not only is the quality of life of the child affected, but also that of the whole family. Active participation of the family is of vital importance to the rehabilitation process. The primary caregiver (usually the mother) has to deal with many challenges while trying to overcome the difficulties arising from her child's condition, but also may face those of not being able to satisfy her own social needs (Ones *et al.*, 2005). It has been found that mothers of children with cerebral palsy have a poorer quality of life compared to mothers with healthy children (Ones *et al.*, 2005).

Perceived social support moderated the maternal stress (Manuel *et al.*, 2003). In a study in Bangladesh, it was suggested that giving practical help to mothers might directly help to relieve the stress of mothers of children with cerebral palsy in developing countries (Mabarak *et al.*, 2003).

2.6.2 Impact of rehabilitation on quality of life

In a study in Cambodia on impact of rehabilitation services on the quality of life of PWDs, it was found that PWDs who had received rehabilitation had a substantially higher quality of life than those who did not receive any rehabilitation (Powell, Mercer & Harte, 2002). As the effects of cerebral palsy do not stop at the age of 16, the traditional rehabilitation approach, which focuses mainly on the achievement of independent walking, might not be the ideal approach for children with cerebral palsy. It

has been proposed that a more independence-oriented, functional approach would be more appropriate (Bottos *et al.*, 2001).

2.6.3 Involving children with cerebral palsy

It has been recognised more and more that children should participate in decisions about their welfare, and that they enjoy and gain skills from participating (Cavet & Sloper, 2004). Many children with cerebral palsy, however, have profound multiple disabilities which mean that they do not have the skills to express their subjective experiences verbally (Selai & Rosser, 1993) - hence the practice in many studies to use proxies, often the immediate carers.

Despite the fact that cerebral palsy is the main cause of childhood disability around the world, researchers are only just beginning to understand the ways in which having cerebral palsy can impact on a child's quality of life (Kennes *et al.*, 2002).

2.7 Conclusion

The WHO/SHIA study (2002) evaluated three CBR programmes, examining the impact of CBR on the quality of life of PWDs. The core findings and interpretations are summarised in the International Association for the Scientific Study of Intellectual Disabilities (IASSID, 2000) document prepared for the WHO. The same eight quality of life dimensions were used by Schalock *et al.* (2002).

Disability is socially constructed. It is not just the impairment that creates problems, but also the manner in which PWDs are excluded. CBR has been in existence for more than 20 years, yet there is still no real agreement on evaluation methods. Many evaluations have used quantitative methods rather than qualitative ones. Quality of life has become of greater interest since it is the overall aim of most CBR programmes.

A key aspect of CBR programmes is that they individualise services and that programmes are adapted to local community needs and circumstances. The individualised participant outcome is measured to see if the programme has really made a difference in the lives of PWDs. Since quality of life is such an individual experience it was felt important to involve the beneficiaries themselves in the evaluation, to document their actual experiences.

This research study focuses on the self-perceived change in quality of life, using a qualitative research approach. In-depth quality descriptions can illuminate what the

perspectives of different people are like, what meaning they give to it, and what the programme has meant to different participants (Patton, 2002).

This study documents the self-perceived change in quality of life of children with a disability and their carers as a consequence of the activities of the ART CBR programme in Dar es Salaam.

University of Cape Town

CHAPTER 3

Methodology

3.1 Research design

A qualitative research design was selected because quality of life is a multidimensional construct that cannot be quantified. To fully understand how someone's life has changed, one needs to be able to describe the different lifestyles of people within their different contexts (Patton, 2002). It is about nuances and how one makes sense of one's life, but also about what one compares oneself to when one decides how well one is doing (Patton, 2002).

Individual in-depth interviews using an open interview guide were conducted with children and carers of children with cerebral palsy who had agreed to be interviewed. In-depth interviews are "open-response questions to obtain data of participant meanings - how individuals conceive of their world and how they explain or 'make sense' of the important events in their lives" (McMillan & Schumacher, 2001, p. 443). When an interview guide is used the topics are decided in advance but the sequence and the wording of the questions are decided upon by the interviewer during the interview (McMillan & Schumacher, 2001). The goal-free evaluation model was used, i.e. the evaluation attempted to determine to what extent the programme participants' real needs were being met (Patton, 2002).

The interview findings, once analysed, were presented to focus groups held with the carers who had been individually interviewed. This enabled the carers to engage with the themes and to comment on the researcher's findings. It was assumed that people would feel more comfortable in a group, and that the interaction with others in a group would stimulate further opinions and ideas. Focus groups are a useful tool for exploring in greater depth what people think, exploring individuals' cultural values and beliefs about health and disease. The group processes can help people to explore their views and generate questions in ways that they would find more difficult face-to-face (Bowling, 2002). The focus group discussions focused on the response to the presentation of the quality of life themes and categories arising from the data analysis – i.e. if the categories corresponded with what the carers found important, and if categories mentioned by only a few of the participants were shared by others.

3.2 Population and sampling

This evaluation focuses on children with cerebral palsy and their carers.

3.2.1 Inclusion criteria

Included in the study were children with cerebral palsy who had been seen by the ART CBR programme for more than two years. For children below the age of ten years, only the parents (who were also their carers) were interviewed. Children over the age of ten were interviewed on their own since they can reasonably be expected to have a recollection of their participation in the programme and to comment on their quality of life. Their carers were interviewed separately. Children were required to have a basic level of communication.

The children with cerebral palsy were divided into three broad groups:

- Children with cerebral palsy who were not able to walk. These children have severe cerebral palsy, or have multiple impairments such as cerebral palsy quadriplegia with mental retardation and/or other impairments.
- Children with cerebral palsy who were able to walk but who also had another impairment such as intellectual disability and/or epilepsy.
- Children with cerebral palsy who were able to walk and did not have other impairments.

Physical and cognitive functioning and severity of impairment have great impact on the future role expectations and general abilities of the child with cerebral palsy. It is therefore presumed that this influences their quality of life.

3.2.2 Exclusion criteria

Excluded from the study were children with cerebral palsy who had been in the ART CBR programme for less than two years, children without cerebral palsy and children above the age of 16 years.

Stratified purposeful sampling was carried out from the data base of the Dar es Salaam programme to select the participants and obtain sub-groups. The ART CBR programme provides services in 10 different local communities within greater Dar es Salaam, with each of these being served by a different CRW.

3.2.3 Sampling challenges

The data base proved to be incomplete, particularly with respect to diagnoses, levels of impairment and level of functioning. For example, cerebral palsy was listed without indicating the body part involved. After the researcher informed and trained the programme staff about the planned research study, each rehabilitation worker, with support from the physiotherapists, revised his/her data base and recorded a more correct diagnosis.

After this exercise each client with cerebral palsy was placed in one of the three study groups. Since the group of severely and multiple impaired children was too large, this group was split into two. One group consisted of multiple impaired children who were not able to walk and the other of children who were severely physically impaired and not able to walk but had no intellectual disability.

There were thus now four study groups with a total of 20 children who met the interview criteria: two children were selected for interview from the data bases of each of the ten CRWs. This selection was carried out by one of the physiotherapists and the researcher, ensuring that the children were from different groups and met the selection criteria.

Final study groups and number of people interviewed

- Group 1:** Multiple impaired children with cerebral palsy who were not able to walk – 5 carers interviewed.
- Group 2:** Children with cerebral palsy and intellectual disability and/or epilepsy who were able to walk – 4 carers interviewed.
- Group 3:** Children with cerebral palsy who were able to walk – 5 carers and 2 children interviewed.
- Group 4:** Children with cerebral palsy only who were not able to walk but had no intellectual disability – 7 carers interviewed.

Thus a total of 23 interviews were conducted - 21 with primary carers and two with children.

3.3 Data collection

3.3.1 Gaining access

Each CRW in the programme received information about the purpose of the study and about how to inform the potential participants. Each potential participant was contacted and asked by the CRW if he/she was willing to participate. If the person was not at home, a letter was left behind with the information and proposed date and time of interview. The names of persons who met the inclusion criteria and who were willing to participate were given to the researcher with the time and place of interview.

3.3.2 Interview guide development

The interview guide was initially developed by the researcher for a similar evaluation done at the Kilimanjaro CBR programme in Moshi, Northern Tanzania, which is run by the same NGO. The guide was originally developed by studying the literature about quality of life. Two workshops were organised with staff from the Kilimanjaro CBR programme in which the meaning of the domains of quality of life in the Tanzanian context were explored and what, according to the staff, the impacts of the programme were on the quality of life of the PWDs and their carers.

The researcher then developed a list of open questions. Programme staff and other professional colleagues went through the questions and the guide was further refined. The guide was developed straight into Kiswahili. It was then piloted in a focus group discussion with carers from the CBR programme in Moshi. As a result of this discussion, it was realised that there were too many questions. Many issues surfaced during the discussion without being prompted. The number of questions was reduced and the order of questions adjusted into a more logical structure.

When planning the study in Dar es Salaam, the interview guide developed in Moshi was reviewed. Discussions were held with the Dar es Salaam programme staff, after which the interview guide was localised. It was also decided to have a broader opening question.

Two carers and a 15-year-old disabled child who was receiving rehabilitation at CCBRT but who were not part of the study were consulted for input into the interview guide. Each was interviewed by the researcher using the guide, and afterwards asked to comment on the questions. They were asked whether the questions were clear and

whether they had suggestions on how the guide could be improved further. After this the final interview guide was developed (Appendix I).

3.3.3 Interviews and focus groups

Each individual interview was conducted in the participant's local community, and in the setting of his/her choice. Twenty interviews were conducted in the participant's home, two at the local support units, and one child was interviewed at school. The purpose of the study was discussed at the commencement of the interview session and informed consent obtained. Each interview lasted not more than one hour.

The interviews were audio-taped, transcribed and translated by the research assistant. After initial analysis of the individual interviews by the researcher, focus group discussions were held with the participants of each group at CCBRT headquarters. The themes and categories which emerged from analysis of the individual interviews were discussed in the groups. The researcher introduced the themes as she had analysed them and the group was asked to reflect on them.

An example of this process in relation to the exercise is the statement: "I have understood from what you told me before that to do exercises with your child is very difficult" [researcher]. The discussion which followed brought further clarity and meaning to the analysis. Participants would confirm the opinion of others by nodding or actively confirming something from their own point of view; others might give a divergent view. The focus group interviews lasted no longer than one and a half hours.

3.4 Ethical considerations

It is of the utmost importance that strict ethical principles are adhered to, especially since PWDs are a particularly vulnerable group. The rights of the participants should be considered throughout the research process (Holloway & Walker, 2000).

Permission for the study was obtained from the Research Ethics Committee of the Faculty of Health Sciences, University of Cape Town (Appendix II).

3.4.1 Autonomy

Participants were informed of their right to refuse to participate without prejudice; that their participation or non-participation would not affect in any way their rehabilitation programme or treatment. Participants were able to withdraw at any time during the evaluation process.

3.4.2 Informed consent

The immediate carers of the children with cerebral palsy who met the inclusion criteria were approached by the local rehabilitation workers to take part in the evaluation. Once a person had agreed to participate, a convenient time and place for interviewing the participant was agreed upon. For the children with cerebral palsy who were ten years or older and who were able to communicate, permission to interview was requested from the parent or grandparent responsible for the child. After this the child was asked if they wished to take part, and assent obtained from the child.

All interviews were carried out in Kiswahili. This is the national language spoken by everybody living in Dar es Salaam. Each participant received a full verbal explanation of the research process prior to beginning the taped interview. Details of the research were provided and of their right of refusal and withdrawal. They were also informed that participation or not would not influence their treatment opportunity.

Each participant was asked to sign a consent form (see Appendix III, Informed consent introductory letter). The information letter initially drafted was too formal for most people to be able to understand; therefore it was read to each person verbally using the letter as a guide, after which they read the consent form before signing.

3.4.3 Risk/benefit

Participants were informed that there was no direct benefit from their participation. Although there were no obvious risks, time was given for the discussion of any concerns that the participants had. Most participants viewed the taping of the interviews positively since it made it clear to them that the programme took their opinion seriously and that the study wanted to reflect precisely what they had to say.

3.4.4 Confidentiality and anonymity

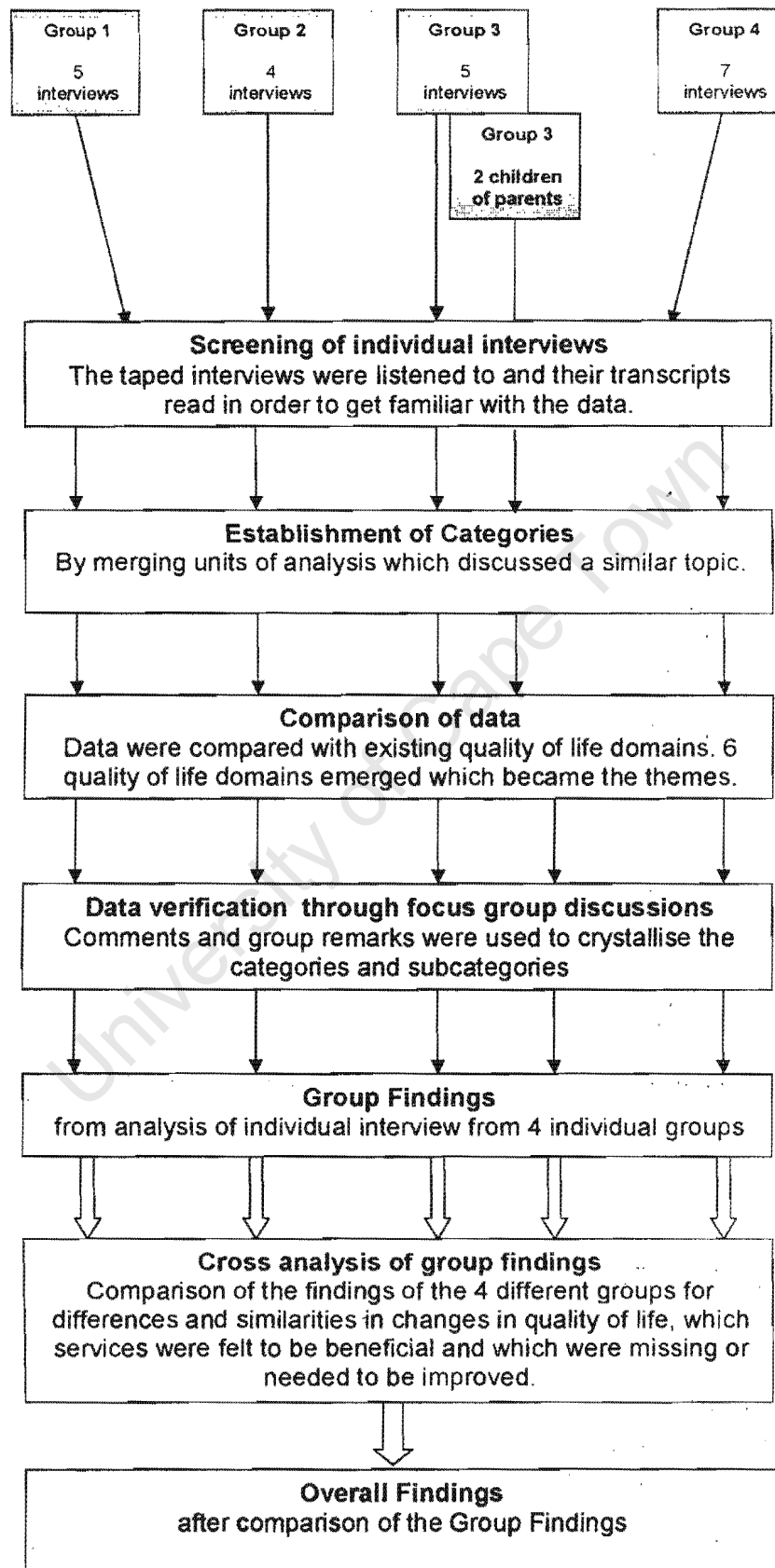
Names of participants as well as of any staff members mentioned remained confidential. Although the researcher knew the names of the participants in order to understand who said what for the analysis to be more meaningful, all references heard on the tape were numerically coded in the written transcript to ensure that confidentiality was maintained. The researcher and the research assistant both signed the consent form whereby they promised to keep all information confidential. Tapes were kept in a safe place, accessible only to the researcher and research assistant. In reporting, no names have been mentioned.

3.5 Data analysis

The interview data were analysed using qualitative content analysis. Content analysis is the process of organising and integrating narrative qualitative information according to emerging themes and concepts. This is characteristically a procedure for analysing written or verbal communications in a systematic and objective manner, normally with the goal of measuring variables and understanding human behaviour within various contexts (Polit & Hungler, 1999).

Analysis focused on the main aim, which was to describe any change in self-perceived quality of life of children with cerebral palsy and their carers involved in the CBR programme. It also focused on the main objectives, which were to describe the impact of the rehabilitation programme on the different dimensions of quality of life of children with cerebral palsy and their carers, and to describe which programme activities have been perceived as being most beneficial to achieve a change in quality of life.

Data analysis flow chart



3.5.1 Analysis of interviews

The interview data from each group (see 3.2.3) were analysed separately using a cross-case analysis. Data analysis consisted of the identification of sub-categories, categories and themes generated, and in some cases shared across research participants (Marshall & Rossman, 1995).

The transcribed interviews were analysed in a series of steps (see data analysis flow chart above). Data analysis began with listening to the tapes and reading the individual transcripts in order to get familiar with the data. The findings of the individual interviews in each group were cross-analysed. An inductive approach was used whereby the individual interviews from a particular group were compared to search for common patterns and categories. These were then aggregated and categorised into units of analysis. The units of analysis consisted of a fragment or consecutive sentences that expressed one theme or thought around a change in quality of life. All units reflecting a similar unit or perception (e.g. exercises) were then merged under sub-category and category headings.

As a next step the different categories and sub-categories were scrutinised in relation to the different quality of life areas (WHO QoL Group, 1994; Felce & Perry, 1995; Schalock, 1996; WHO/SHIA, 2002). The quality of life themes which emerged were physical well-being, emotional well-being, spiritual well-being, personal development and material well-being, social well-being and confidence in society to fulfil its human rights obligations, especially related to education. These quality of life domains became the themes. Below is an example of the coding of the interview data:

"It is now almost two years since I started going there. She has been doing the exercise quite well but she has not yet been in a position to do something on her own".

Theme – Physical well-being; Category – exercises; Sub-category - Although doing exercises, not much improvement.

3.5.2 Analysis of focus groups

Subsequently the focus group transcripts were read and the added insight helped to further clarify the categories and sub-categories. It allowed for greater discrimination and differentiation. No new themes emerged. In this way a categorisation was obtained consisting of six domains of quality of life, each of these divided into categories with their accompanying subcategories. When divergent views appeared under a theme or category these have been mentioned. The researcher has tried to reflect the exact meaning of what the participants said.

3.5.3 Cross-analysis of the study groups

After presenting the findings of the different groups a cross-analysis was done whereby the findings of the different groups were compared and analysed for similarities and differences in changes in quality of life. Note was taken of which services had been identified as being helpful and which services were felt to be lacking or needed improvement. This is further elaborated upon and reflected in the discussion in Chapter 5.

3.6 Validity/trustworthiness

It has been proposed that trustworthiness is utilised to guide the search for quality in qualitative data (Guba & Lincoln, 1989). Trustworthiness exists when the findings of a study represent reality (Holloway & Wheeler, 1996).

Guba and Lincoln (1989) propose that credibility, transferability, dependability and conformability form the basis for trustworthiness and provide an effective guide for qualitative researchers to attain quality and effectively evaluate their research. Others apply a more constructionist viewpoint. Madil, Jordan and Shirley (2000) stress the importance of multiple realities and meanings, and promote the use of internal coherence, deviant case analysis and reader evaluation to show quality and trustworthiness of the research. They define internal coherence as the extent to which a given analysis hangs together logically without contradictions. Deviant case analysis means showing extreme examples and relates to showing the context and limits of an emerging theory. Reader evaluation can be understood as the degree to which the study contributed to readers' understanding and insight. To facilitate this they propose that verbatim quotations or extracts from the data be provided to allow readers to arrive at their own interpretations, thus drawing the reader into the researcher's discoveries and allowing the reader to see the worlds of others in new and deeper ways (Finlay, 2006).

3.6.1 Credibility

Presentation of faithful descriptions focuses on the confidence in the truth. A study is viewed to be credible if the research findings show a logical relationship, are grounded

in and substantiated in the narrative, and the original population considers the reports to be accurate (Huberman, 1994).

After initial interviews the researcher represented the multiple realities of the immediate carers and the children with cerebral palsy as accurately as possible. During the interview process questions were reframed, repeated and/or expanded on different occasions. Data were analysed for recurrent patterns. The researcher has worked in and managed a CBR programme in Tanzania for more than 10 years, and is therefore familiar with the work and the issues that the people brought up. The researcher's experience of working with PWDs and their families within local communities did contribute to interpreting the findings.

Since the researcher was not familiar with the Dar es Salaam programme she familiarised herself with the particular research setting by collecting background programme information. Existing programme documentation was read, including the Annual Report of the year prior to the study. The researcher had a meeting with the programme manager, who further elaborated on the functioning of the programme and the staffing situation.

Participants were made to feel at ease, and it was stressed that this evaluation should contribute towards improvement of the programme and services. Participants were asked to reflect on both positive and negative aspects of the programme. They commented that they really appreciated the opportunity to give their opinion, since to them this was evidence that the programme took their opinion seriously.

In a study such as this, feedback to the participants is important after the results of the evaluation have become available, since the exercise has created certain expectations. 'Member checks' or feeding findings back to informants (Miles & Huberman, 1994) were also utilised. The themes and categories which had emerged from the individual interviews were reported back to the participants, which gave them an opportunity to discuss the findings. Each group was given an opportunity to collectively reflect on what they had said. Sitting together as carers of similar children, created a very conducive atmosphere for sharing information.

3.6.2 Transferability/relevance

Due to the small sample size of this study the findings cannot be generalised. The study is based in Dar es Salaam with carers of children with cerebral palsy who participated in a CBR programme. This particular group might not relate to a similar

group living within a different environment. These findings may, however, be found relevant and useful to similar CBR programmes. They might assist them to improve their programme planning and development.

3.6.3 Dependability

A study is dependable if it can be audited. Ulin, Robinson, Tolley and McNeill (2002) argue that dependability is reliant on a sound research process that is consistent and has been undertaken within the paradigm and methodology as proposed. Field notes and a log were maintained throughout the study and functioned as an audit trail. This provided a record of the research journey. Field notes were kept of the experience and used to reflect upon during the analysis. Verbatim transcriptions were made from each taped interview.

3.6.4 Reflexivity

The qualitative researcher is part of the research process and influences the process. The researcher is a qualified occupational therapist who has worked with PWDs and their families for more than 20 years. The researcher is originally from The Netherlands but has lived and worked in Tanzania for the last 13 years. For the last 10 years she has worked as a manager of a CBR programme run by the same NGO in a different city. Most of the work was with and within local communities.

The researcher's experience as a therapist/manager has brought different qualities to the research project. It provided added insight into the situation of PWDs which helped during the interviews, since the researcher could show empathy and understanding. However, there was the temptation to offer advice and to sort out problems instead of listening for the meaning of the participants' reflections and experiences.

Use was made of appropriate interviewing techniques such as open-ended questions and probes. Information gained from the interviews influenced the nature of the probing questions in the subsequent interviews. Therefore, as the research progressed certain issues which had emerged in previous interviews were further explored.

The position of the researcher in the organisation might also have influenced the responses of the participants, since they may have thought that the researcher had power in the organisation, and therefore there may have been raised expectations. The researcher was careful not to imply that by doing this evaluation any direct benefit would accrue to the participants.

3.6.5 Transcription of interviews and focus groups

Interviews were recorded, transcribed and translated by a research assistant. The researcher read both the English and the Kiswahili text and made corrections when required. The analysis was written in English by the researcher.

3.6.6 Conformability

The researcher endeavoured at all times to link the data analysis to views expressed by study participants. Although the researcher is a foreigner, the contextual experience of living in the country facilitated interpretation of the data. It assisted in understanding from what type of living circumstances, family relationships and general attitudes people were speaking. It gave an added insight not just into hearing what people were saying but also into what was not actually said and what was implied (e.g. that people will often feel that they need to praise before they can criticise).

3.7 Conclusion

The evaluation attempted to determine the self-perceived changes in the quality of life of children with cerebral palsy and their carers involved in the CBR programme. The children with cerebral palsy were divided into four groups who had different functional levels; a range of children from the very mobile to those who were very dependent. Individual interviews using an open interview guide were conducted with 21 carers of children with cerebral palsy and with two children participating in the ART CBR programme.

The interview transcripts were analysed first, using an inductive approach whereby units of analysis which described a change in quality of life were coded. Similar changes were then grouped together in categories and subcategories. This was followed by comparison of the data with existing quality of life domains. Six quality of life domains emerged which became the themes.

The findings were presented back to the carers in four focus groups which were constituted according to the initial grouping of the children's functionality. This enabled the carers to engage with the quality of life themes and categories which had arisen from the analysis. The researcher was able to verify if the findings corresponded with

that which the carers found important and if the themes were meaningful. Each group transcript was analysed separately.

At this stage the findings of the 4 groups were cross analysed which led to the overall findings. The findings of the individual groups will be presented in the following chapter. The overall findings will be presented in Chapter 5, together with discussion and implications of the study for further programme development.

University of Cape Town

CHAPTER 4

Presentation of findings

"What we know of the world we only know through our experience of it: we cannot even know another person's experience of the world. The best that we can do is to interpret the experience of others, that is, their expressions of their experience as they go about the business of interpreting it for themselves" (Smith, 2006: p. 210)

4.1 Themes which emerged

The aim of the study was to determine if there had been any change in self-perceived quality of life of children with cerebral palsy and their carers. Main objectives were to describe:

- the effects of the rehabilitation programme on the different dimensions of quality of life of children with cerebral palsy;
- the effect of the rehabilitation programme on the different dimensions of quality of life of the carers of the children with cerebral palsy; and
- programme activities perceived as being most beneficial in achieving a change in quality of life.

Transcripts of interviews with individuals and focus groups for each of the study groupings (see 3.2.3) were thematically analysed as described in Chapter 3.

The main quality of life themes which emerged from the data analysis were: physical well-being, emotional well-being, spiritual well-being, personal development including material well-being, social well-being and educational rights. These themes are presented for each group.

Each theme has been further subdivided as follows:

- **Physical well-being** includes health, fitness, mobility, speech/communication, health and rehabilitation services, and pain.
- **Emotional well-being** includes issues such as personal satisfaction, fulfilment, stress, mental health, self-esteem, status and respect.

- **Spiritual well-being** refers to issues such as faith, belief and religion.
- **Personal development** relates to issues such as competence in doing daily activities, productivity, livelihood activities.
- **Material well-being** refers to issues such as finance, housing situation, food situation, contributing to cost of rehabilitation.
- **Social well-being** includes personal relationships, community involvement, and participation in social and leisure activities.
- **Rights** deals with access to information, access to and quality of educational services, and in one group it also means access to health services.

A diversity of experience and opinions for each group was found, and are presented separately. Certain issues were specific to a particular group, but there were also similarities across all the groups. The format of presentation of the findings is the same for each group. Findings are presented using the quality of life domains as themes.

4.2 Group 1: Children with cerebral palsy who are severely and multiple disabled

This group of children are severely multiple disabled. All of the children have cerebral palsy affecting all four limbs (quadriplegia) together with other impairments. They are not able to walk or talk, and are fully dependent on their carers.

Five parents were interviewed. Four children have a moderate to severe intellectual disability, and one is blind and has epilepsy. Demographic information is provided in Table 4.1. According to the carers, these children became disabled soon after birth.

"When X was born he got a severe fever, it was not only severe but it was accompanied by convulsions." Parent of child 5

Table 4.1. Demographic information, group 1

	Participant carers	Age	Sex	Impairment	Ability	Onset of impairment	Social situation
Child 1	Mother	8 yrs	F	Multiple – CP + epilepsy + intellectual disability	Unable to stand or talk; fully dependent	At 6 months noticed that child was not able to do anything	Child lives with parents and one older sibling and a cousin with intellectual disability looks after the child
Child 2	Mother	7 yrs	M	Multiple – CP + blind + ? intellectual disability	Unable to stand or talk; fully dependent	Developed high fever just after birth and again at 3 months with convulsions. At this point he was diagnosed as blind	Child lives with parents, father is a driver. Mother is a housewife – has no time to do something else. Has a twin who now moved away to school
Child 3	Mother	6 yrs	M	Multiple – CP spastic + intellectual disability (arrested hydrocephalus)	Unable to stand or talk; fully dependent	7 months premature at birth; neck weakness, diagnosed after a few months with hydrocephalus; no shunt	Child lives with parents, father is a driver and one younger sibling
Child 4	Mother	11 yrs	F	Multiple – CP + intellectual disability	Unable to stand or talk; fully dependent	After birth she had yellow fever, which affected her brain.	Father left when child was 2 yrs old. Mother has 3 children (2 with first husband and 1 with another boyfriend). Mother lives with parents
Child 5	Father	5 yrs	M	Multiple – CP + intellectual disability	Unable to stand or talk; fully dependent	After birth he developed severe fever with convulsions	Child lives with father and stepmother. No other children

CP = cerebral palsy.

4.2.1 Physical well-being

4.2.1.1 Importance of physical exercises

Physical exercise is the main service offered by the programme, and was recognised as being very important for the children. However, despite the parents' commitment to regular exercising, children made only small improvements.

"It is now almost two years since I started going there. She has been doing the exercise quite well but she has not yet been in a position to do something on her own. Anyway, there is some slight improvement, for instance in sitting. Even though she used to sit just from the beginning, she has at least improved it. She just pulls herself on the floor and she cannot stand. She can hold something hard but not like rice."
Parent of child 1

Parents see that the exercises work for other children, and hope that they will see similar improved function in their children.

"I think she will fare well the more we continue with the exercises. I think he will be improving because of the exercises he does rather than just sleeping. At first he could not even move his hands but right now he can." Parent of child 3

The carers acknowledge that they have not seen the physical exercises work much so far, and that this is de-motivating. Exercises are not always done regularly, and they feel guilty about this. Because some of the exercises are painful for the children there is a tendency to avoid doing them since they are reluctant to cause suffering and are afraid to do something wrong.

"For instance, for my case, I started the exercises in 2000 and until now, I still do although the improvement is quite little." Parent of child 3

"The only thing I struggle with is doing the exercises at home but when the day comes for going to the centre then I take him. I tell you, my child really cries. The day I do not go for exercises everyone just knows that I am absent. Immediately you enter that building, he starts crying. Even at home, even if you just touch his hand and stretch it he starts crying on the spot. There you need to have enough courage to do the exercise." Parent of child 2

4.2.1.2 Stress of getting children to exercise venue

In this group none of the children is ambulant, and as they grow it has become more difficult for the carers to carry them to the exercise venue. They are concerned that the child does not get enough exercise and would prefer to be visited at home.

"I still go but not as much as I used to because she is too big and therefore heavy for me to carry her to the centre. When I take her frequently, I become sick because of the ulcers." Parent of child 4

"... maybe I am sick and there is no one else to take him for the exercises. If I fall sick for a whole month, it means for that whole month he will not get any exercises, as the father is afraid to do the exercise on him." Parent of child 2

4.2.1.3 Difficulties with adaptive equipment

Carers reported that they frequently had difficulty in obtaining equipment due to lack of availability.

"I would like the organisation to continue helping me so that she may get some equipment to improve her more. Like a standing frame. I have been waiting a long time but they do not have it." Parent of child 4

Equipment, when obtained, was not always appropriate and did not always fit.

"I was also told to buy her shoes and I actually bought them. She wore them once and they seemed to be big so I took them back to CCBRT and they shortened them ... Every time she wore them they caused blisters on the legs as if she was burnt. ... now I don't use them at all." Parent of child 4

Carers are told it is important for the child to use the equipment, and this puts the carer in a difficult situation since it is not easy to comply with the instructions.

"There are times when he does not want to sit so when you put him on the chair he slides. He feels like you are mistreating him. He does not always cry because I am always close to him. He does not like that chair ... When I put him to sit down, he bends his neck in front so after some time he becomes tired and he tries to bring it back upright and in so doing that is an exercise he does to herself, which is better than just lying on the bed without any support." Parent of child 3

The children in this group are severely disabled and it is unlikely that they will be able to go to school. Due to the NGO's policy of providing wheelchairs only for school-going children, they were therefore not eligible for a wheelchair. However, the carers thought a chair would be beneficial for their child, since it might help solve the mobility difficulties and provide an opportunity for more participation and stimulation.

"I was also making a follow-up for a wheelchair but they told me that I will only be considered when he starts school. So I told them that I have been told by the doctor not to carry heavy things, then they told me they will think about it." Parent of child 2

"She also needs a wheelchair so that I can push her outside for her to see the environment so that she may feel ... There are just many roads out there. She really likes walking outside there because when I take her for the exercises she is excited and laughs at people. She becomes excited because she stays inside the house most of the time. So when she goes out she really rejoices." Parent of child 4

4.2.1.4 Communication

Communication with their children was important to the carers. Even if children are only able to communicate at a very basic level it enables a relationship between carer and child to develop.

"She now knows and understands some things. She knows when she is thirsty and can ask for water, she knows I am the mother and therefore she calls me mum. She is gaining some understanding as she grows. she knows all of her close relatives including the brothers. She knows this is my brother and therefore I should call him brother (kaka), but then she cannot go beyond that." Parent of child 4

"He imitates the sounds he knows. When the father comes and speaks to him, he automatically knows he is the one but if a stranger speaks, he listens very carefully to the voice because he is not familiar with it. He can then decide to respond back. He can respond back if you call him." Parent of child 3

The mother and child develop their own communication system. However, carers were not always sure how much their child understood, particularly if the children are completely unable to talk. No mention was made of any exercises that they had been told to do in order to improve communication.

"If maybe you stay for a long time without coming to look at him, when you now appear he gets angry why you had left him for so long, and because he cannot talk, he really cries. He feels like you have deserted him and so he becomes worried and that's why when he sees you he is unable to talk so he expresses it by crying until you go and pick him up." Parent of child 3

"Because, when I tell her something she really looks at you. Therefore, I have not understood whether she is able to understand." Parent of child 1

4.2.1.5 Health

The children have a number of health problems and are often unwell. This results in loss of functions already achieved, which is very stressful and frustrating for the carers. They try to prevent their children from getting ill.

"He can improve very well but then when he is attacked with fever he drops down. Even quite recently, he was faring on very well but then he was discovered to have a growth in the nose and so he was operated on. Since he was operated on 1st February, I can see that he has really gone back unlike in the past, because he could sit upright and use his hands." Parent of child 3

Obtaining the appropriate medicines can be difficult. CCBRT hospital provides affordable medication for the treatment of epilepsy; however, prescriptions must be obtained from other health care providers. Since the services are not well coordinated, errors occur and children may not be optimally managed. The mother whose child has epilepsy explains her situation:

"She can convulse even three times a day. ... There are times when you go you find the medicine is over. This is the second month she has not been using medicine because of the card. ... I came back and went to CCBRT and told them that I had gone to Amana where they told me to go to Muhimbili and at Muhimbili I was told to present a note from Amana. They advised me to go with the note that shows where my child was treated ... I went to Amana and they gave me the note last week so when I went on Friday I was told that the doctor was sick and therefore was not at work so they told me to try on Monday ... [Mother talks with tears in her eyes] They [CCBRT] said the card I had was too old. They therefore wanted a new card so that I can be seen by the doctor." Parent of child 1

4.2.2 Emotional well-being

4.2.2.1 Carers need hope for improved physical function

Caring for severely disabled children is very stressful. There is minimal improvement and they need a high level of personal care. The mothers are the main carers and reported having taken their disabled children to hospital when ill and for regular exercises, yet despite their many efforts the children remain very dependent for almost everything. The mothers love their disabled child and despite the stress of the continual caring they need to have hope that things might eventually improve.

"There are some people who encourage and by telling you to just go on with the exercises. I thank the CRW of CBR because she normally tells me not to lose hope that I should continue with the exercises day after day as I don't know how tomorrow will be. She can improve so well. She tells me if I were not doing the exercise, my child would not be the way she is now. He would be so stiff." Parent of child 3

It might be too confronting and de-motivating for carers to look too far ahead.

"I do not know what he will be like later, because I have not tried to vision in the future." Parent of child 2

4.2.2.2 Consolation of knowing you are not the only one

Mothers feel blamed for having given birth to a disabled child and think that they are the only ones going through this. This raises their anxiety. A participant explained her feelings of isolation before meeting carers with similarly disabled children:

"At first before meeting with other parents, I used to sit alone and cry the whole day as I think about my daughter. After seeing some other parents who had children like mine, I no more cry because I know I am not the only one. I continue consoling myself. I realised that I was not the only one with such a child, that there were many others too. I used to think that God had punished me yet it was not so. We are all over with such children." Parent of child 4

4.2.2.3 Coping with stress

Having a child with a severe disability is very stressful. Attitudes of members of the extended family further complicate matters, as they blame the mother for having given

birth to a disabled child. The mothers experience more negativity from the father's family and feel more supported by their own family members.

"So it is usually pressure from the parents and you find that if the man is not strong enough he will actually leave you with the kids and run away." Parent of child 4

"It reached a time where my husband was told to desert me. ... They even went to his place of work and told his employer to sack him and it is true he was sacked. They later said that we had offered that child as a sacrifice to become rich." Parent of child 2

"And my mother does not stay far from where I stay, during the weekends she can tell me I know you are tired so you bring X here so that you can rest. But on the other side there is a problem. Most of the time it is the husband's relatives that have a problem." Parent of child 3

One mother explains that her husband is struggling, and feels that life is no longer worth living. He is contemplating suicide because he longer is able to cope. His family wants him to leave her and the child, but he loves them and is committed to them. This is for him an unbearable situation. He feels torn between the child and his wife on the one hand and his family on the other side.

"There is a time I was admitted in hospital with X ... his sisters told him that he is following the woman's tribe and people instead of following his own people. He was really hurt by that statement ... He says I remain with you otherwise I kill myself ... So I told him I don't refuse you to kill yourself but before doing that take this child hold her and try to visualise who he will be left with and where he will go as life has become so tough. ... So he told me the next resort is that we die all of us provided all these problems come to an end. I told him you must think twice of what you want to do. If you are tired of living and you want to surrender your life to God, just kill yourself and leave the children for me. But he gets all these thoughts from his parents at home. They tell him I am not the right woman he can stay with. Why should she give birth to a disabled child while your brothers do not have disabled children? If he goes to his home, when he comes back he comes in a very bad mood because of what he has been told." Parent of child 3

The children experience a great deal of pain, particularly during exercise. This causes further stress. Mothers explain that the fathers refuse to be present when the mother does the exercises as it is too painful to watch.

"You feel pain at the heart but you know it is for her own good so you just continue. Though she is your own child, you do as if he is not your child just for his own sake." Parent of child 4 in focus group

"he cries until the father tells me to stop doing the exercise. He cries so bitterly..." Parent of child 2

4.2.2.4 Carers want their child to be like other children

Carers observe that even though their children have very little functional ability they are able to enjoy themselves.

"He plays whilst lying down. If he hears a nice song on the radio, you can hear him singing the song - of course not pronouncing the words but you can get the tune. He turns and rolls himself on the bed so happily..." Parent of child 2

However, at times the children can get very frustrated with their inability to do things.

"She really wishes to play but the nerves in the hands do not allow her. She can see something and moves towards it but when she tries to pick up the thing, it becomes difficult. That makes her cry with anger." Parent of child 4

The carers believe that the little improvements the children have made make them feel more human.

"I think that right now she at least sees herself as a human being unlike in the past days. In the past she used to lie down the whole day but when I started going to CCBRT, they advised me to find a chair for her and she can now sit and feel like other people." Parent of child 4

4.2.2.5 Children enjoy being and playing with other children

The children enjoy and become happy being with other children.

"There are children from our neighbours and I also stay here with my brother's son. When they sit outside here with him, they are always close to him. It is something to be grateful for ... He is not able to play with other children, instead he just rejoices when others are playing." Parent of child 5

Not all children have the opportunity to be with other children. One carer lives in such a cramped environment that there is no shady place outside to sit.

"Because of the way she is, she stays indoors most of the time. Our place is so small that you cannot put her outside and after a short while, the sun will be falling direct, so I cannot leave her to sit in the sun throughout." Parent of child 4

Not all of the neighbouring children want to play with their children, and some neighbours find their children strange.

"Other children come to play with him but then you cannot force them to stay around. They can stay for two or three minutes and then disappear. At times, you can even finish two days without seeing any child around this place and when they come some just stare at him and then walk away." Parent of child 2

"The neighbours as usual find her strange. When they sit and chat with other children they always find her strange." Parents of child 4

4.2.3 Spiritual well-being

4.2.3.1 Hope and support from prayer services

Spirituality and religion provide the carers with emotional support. Carers take their child to the prayer services; it does not seem to matter whether they are Muslim or

which denomination of Christian Church they belong to. By taking their children to prayer services they get strength and hope for spiritual healing.

The programme offers them physical exercises but the carers are also in need of spiritual support, especially since the exercises do not make a great difference. They feel strengthened by these religious spiritual services.

"The Pentecostal Church they do not really take care of me, but it is that they comfort me. They just encourage you when you go. There is a time my child used to cry at night from 10 pm till 5 am in the morning. After taking him there he was prayed for and the problem ended. Even recently, when he had refused to eat I took him for prayers and right now he is trying to eat." Parent of child 2

"And they tell you something good comes slowly. First, you will remove the burden from your heart and then it will no longer be a problem." Parent of child 3

"The burden of saying God is against you. Not crying every time and saying how God is against you." Parent of child 4 (focus group)

Carers are afraid to look too much into the future, and look for spiritual meaning and support. God is the one who knows and is able to change things.

"I can't know about her future. I do not understand if she will learn. It is only God who knows. She can go [to school] and God willing she can also improve. We pray to Him because He is the one who has the power over everything." Parent of child 1

4.2.4 Personal development and material well-being

4.2.4.1 Dependency

Carers look for small improvements, even though they realise that the children remain fully dependent.

"She can sit, sleep and even lift herself up to the level. She can even move from one place to another, but she cannot stand on her own unless there is support." Parent of child 1

"Right now he can sit and he stands with support and I am trying to make him walk, but he has no balance to stand very well. He does not move on his own. When he is lying down he can roll himself." Parent of child 5

Feeding is time-consuming and is anxiety-provoking as the children are very particular about what they eat. The mother finds it important that the child eats well to be healthy. The children sometimes refuse to eat. This creates concern. Parents are also told to train the child in eating firmer foods, which then requires even more time.

"He has to be fed just like a baby. He does not chew. I thank God that he can eat things like soft ugali [maize porridge] and rice. But if you place your finger in his mouth he can bite it so I wonder why he is unable to chew food. He really chooses what to eat and what not to. The food must be tasty for him to eat. If it is not tasty he completely refuses to eat. If the food is tasty he eats without any problem ... But then I have to spend about half or even one hour just on feeding him because he takes a lot of time to chew up food." Parent of child 3

Eating is one of the few opportunities where the children have control and can make choices – i.e. where they have power. It is a time when the mother has to be very attentive and it creates stress.

"I can prepare something special for him then he refuses to eat. So I can cook for him bananas then after some time I also fry chips for him which I am forced to chew for him ... So when you chew for him such things he sometimes eats and other times he refuses." Parent of child 2 (focus group)

4.2.4.2 Mothers' lives revolve around the child

Mothers' lives revolve totally around their children with a disability. Caring for their disabled child is a heavy burden, and they spend so much time caring for their child that there is little time for anything else. Mothers are no longer able to work or earn a living, and there is little room for personal development of the mother.

"I was a tailor but I have stopped because of my child, I am now dependent on my husband who is a driver." Parent of child 2

They feel that they are the only ones who can take care of their child properly and are unable to leave their disabled child with anybody else. This caring burden creates tension - of wanting to protect their child and loving them but also feeling like a prisoner with no way to escape.

"I was thinking of leaving my child with a helper but then many people have been telling me that it will first be hard. If he at least knew how to feed himself it would be better. For instance, I have just given him porridge after a short while I will have to give him milk but if it were someone else staying with him here, it would be difficult." Parent of child 3

"I can leave her but then I pity those I have left the child with because they cannot take care of her as I do myself. For example, if she helps herself I as a parent can clean her up but it is hard for someone else to do it. The person feels Her disabilities are too much. Those that I stay with are better because they at least see what I do and they try to help me but someone who does not stay with him cannot make it." Parent of child 4

Mothers feel powerless to change much about their situation. They get support from somebody - if not their partner then another close relative. They feel CCBRT helps to some extent, as the exercises give hope for improvement. In addition, knowing that they are not the only one in that situation also helps. However, generally they feel that they are in need of more support.

"It was hard for me because in the first place I never got any idea of telling myself to start any business. I just used to sit all the time looking at my child hoping for someone to come and help me. Generally life in the past days was not good. For now it is at least better because I even have faith when my child is given exercises and I also meet

others and we exchange different ideas and I now feel better than in the past days."
Parent of child 4

After the first interview this mother decided to train her sister to look after her child and do something to earn some money. Already by earning a little bit of money herself and no longer being completely dependent on her relatives she felt that she was given more respect.

"I get something small. Even now, I can see I receive some respect unlike in the past days when I was looked down upon." Parent of child 4 (focus group)

One mother benefited to some extent from participating in a women's group at CCBRT which runs an income-generating activity. It gives her a feeling of positively trying to improve something in her life, but she looks at how she can improve it further.

"There is nothing I do, apart from the tablecloths that I take [from CCBRT women's group] to knit, but still I have not yet become an expert in them. I am still learning. I like it because they really help us. It is better if you take those cloths. It is important because there is no other business I can do because I am always on and off. I sit with her as I do my own work. There are people who take and they knit so many of them and get money. But for me I can even finish two weeks without finishing because when I come back home there are other things to be done also, so getting time to sit down and knit is like..." Parent of child 1

4.2.4.3 Poverty

Families have less income because they have to take care of their disabled child. Women who used to do some activities to support the income of the family are no longer able to do so due to the intensive care needs of the child.

"I spend a lot of time with him not doing anything else. I do not have a job because of him. My husband is a driver. I don't do anything. I depend on my husband. I love to have my own job because I am a qualified primary school teacher but I am unable to work because there is nobody to leave my child with because I spend most of my time taking care of him." Parent of child 3

Lack of money is a constant issue in these carers' lives. The main issue for them is the loss of independence and poor self-esteem which results from lack of resources. They feel that if they had a better income they could stand up against and better deal with the negative attitude of relatives.

"For instance, I do not work and he [her husband] does not work. I think that is why we are looked down upon. I think if I had my own good job or my business where I can wake up in the morning and say I am going or I have my own income, I don't think such things will be there." Parent of child 2 (focus group)

"Having a disabled child brings many problems in the [extended] family. Maybe if you had your own business that earns you income, it becomes better." Parent of child 3 (focus group)

4.2.4.4 Having a child with a disability is costly

Food is an important aspect in the life of a child that otherwise has so little. They are very particular about what they eat and they fall ill easily. Having to buy special food for these children creates a further strain on the household budget.

"She needs special food and taking care of her is more expensive than any other child. And if you decide to stick to what she wants you can even finish up spending Tsh. 5000 per day just on her." Parent of child 4 (focus group)

Carers are willing to contribute towards the cost of the equipment, but because of the many other costs that they incur with their disabled child they need to budget and save up for it. Carers get extremely desperate. They have children who are not improving much, are told this piece of equipment might help their child, and really want to try to get this money together.

"Yesterday I was told that my child will now need a standing frame because she is supposed to practise standing. I asked the physiotherapist about it yesterday and she told me that I have to contribute some amount. Therefore, I told her it is okay ... if I get some money, I will inform you. ... I told them when I get money I will come ... because right now we have used a lot of money when he was admitted at the hospital." Parent of child 3

One mother did receive some financial support for buying a piece of equipment. She is extremely grateful.

"I did not expect to have it ... it was too expensive. I was very happy after buying especially because there was a reduction in the amount I was supposed to have paid. I did not expect to have such a thing in life." Parent of child 1

4.2.5 Social well-being

Having a severely disabled child changes not only the relationships within the family but also those with extended family and neighbours.

4.2.5.1 Effect on siblings

The children have often a close relationship with their siblings. Siblings are the ones that play with the disabled child and sometimes help with some of the care.

"Most of the time she is with his younger siblings who he plays with." Parent of child 4

"The other twin is in A [a town in the north of the country]. I took her (the twin) there because she refused to go to school because of her disabled twin brother. If you tell her to go to school she would ask why is my brother not going, then she tells you I am also not going. So I decided to take her there [to her grandparents]." Parent of child 2

Due to the central role of the disabled child, the other siblings might lose out, since they are expected to be accommodating and supportive, and sometimes help more than they should be expected to. This means that some of their rights are infringed upon.

"For instance, if now I want to leave, I have to wait for the brother to come back from school ... I leave him with the brother. He is 4 years old. I just leave them because there are a lot of people around this place. ... When he is with the brother, he cannot cry." Parent of child 3

4.2.5.2 Varying support from partners

The support from partners is very varied. There is a lot of worry about the child. Two mothers feel supported by their husband: when their husbands are at home, they help. The one father was emotionally touched that his wife - who is not the biological mother of the child - so lovingly takes care of the child.

"I really thank God for this woman because after bringing X here, she takes care of him as her own child. She loves him so much. [Crying] I am so grateful. For sure I did not expect her to take care of him as her own child. These tears I am shedding are tears of joy that hurt. I really appreciate getting someone with such a good heart. She provides anything the child needs. She takes good care of him." Parent of child 5

However, one mother feels that the father is not able to cope with it anymore, and leaves it all up to her. This is very difficult for the mother. She feels it as a heavy task, but one which she cannot give up.

"From the way I study him I see that he is tired, so I have decided not to give up because I am the one who knows her improvement. If you decide to leave her that way, she becomes worse." Parent of child 1

One other mother was left by her husband, and she is now living and depending on her relatives. The programme and her belief in God has helped her to cope with the situation and to come out of her depression.

"I am just here with my parents for the time being. But, I at least have faith unlike the past days when I was abandoned. I had a lot of thoughts but I am okay and I thank the Almighty God. I just sit at home. They are the ones who struggle and help me. I also have some brothers and sisters who when they get something they come and help me." Parent of child 4

4.2.5.3 Support from relatives

The mothers say there is a difference in attitude between their relatives or the relatives on their husbands' side, the latter causing them a lot of problems.

"Most of the time it is the husband's relatives that have a problem. The house we were staying in was a family house. So they said let's sell that house then we can see where he will go with his disabled child." ... "On a day like Sunday or a Saturday, I take her to

my mother, and if they have a lot of work they put her on the chair to watch TV. They say that having a disabled child is God's plan." Parent of child 3

"I have a sister who stays at Manzesi. She often comes to visit. She was the first one together with her husband to start helping me." Parent of child 1

One father stated how he got a lot of support from his family. His child stayed for a while with his sister who lovingly looked after him.

"My younger sister took him and made sacrifices to stay with X, but then I felt it was hard for me to leave my work here to go and check on him. So I decided to take him back because of the inconveniences, but then she wanted to stay with X." Parent of child 5

One mother receives support from a relative, a young aunt of the child. She has an intellectual disability, but is of great help to the mother. The mother is afraid that the aunt's parents will want her back.

"I leave her younger brother with his aunt. ... She is a grown up but she is not really okay upstairs, so I just leave him with her to take care of him. I mean she is someone that needs to be told everything. There is nothing she can do without being told. But she now knows how to take care of my child." Parent of child 1

4.2.5.4 Relationship with neighbours

The relationship with neighbours varies a lot. Some are very understanding, willing to help, and include them; others do not want to be confronted with the child, especially when they give a party.

"But the family I stay with really understands me because I have not kept my child hidden. They invite me ... they tell me 'yes we know you have that child but we cannot isolate you because of the child as you are one of us'. I have one neighbour who tells me that in case I am going somewhere far, I just need to feed the child well and put him on the chair and take him to her as I go wherever I am going to." Parent of child 3

This parent goes on to explain that others have a more negative attitude:

"But there are some people for whom even just looking at you is a problem. They say 'we cannot invite her as she has her own problems. She cannot even contribute anything, as she is full of problems'." Parent of child 3

She also has to defend the right of herself and her child to participate:

"There is a wedding I once attended and I was asked why I went with my disabled child. So I asked them 'who do I leave the child with, yet this function concerns me?' I told them X is a human being just like me and you, so I don't see any need of leaving him at home. ... I was defending my child so that they may not take him as something so strange, because they can also get such a child or even worse than X." Parent of child 3

4.2.6 Rights

4.2.6.1 Right to education

None of these children is going to school. The carers however want their children to go to school since education is important for development. Normally children start school when they are seven years old. It is difficult to accept that your child might not go to school. School is about the future - they feel that their child is being denied a future.

"I am really hurt about his schooling. I am thinking of how he can go to school, but there is nothing I can do. If you look around all his age mates go to school except him. That really worries me a lot. He is 7 years old. I hear there are schools but then he should be able to help himself and hold [be continent] - now X can't. I now don't know how it will be..." Parent of child 2

"I feel that if I don't take her to school I will be denying her her freedom. She likes going but her physical body does not allow her." Parent of child 4

Carers know that the programme advocates that disabled children who are able to walk a little be placed in regular schools, they are not sure if something could be done for their children. They would like to look into it. They all hope that their child will be able to go to school, but do not seem to have pursued it further.

"I think there are no such schools here in Dar. But I know those that can maybe walk using crutches are taken to normal schools, even though teachers do not accept them. If a child is taken to school by the parent and the child is not accepted by the teacher, these ladies go to the school and they talk on behalf of the parent and so the child is accepted. I now do not know about children like mine..." Parent of child 1

"Still I am not sure if there are those that accept such a child with many problems like my son, who cannot talk and also cannot walk. I don't really know if there are such schools. If at all they are there then... I have not followed up if they are there or if they receive children of such a condition." Parent of child 5

4.2.6.2 Right to health care

The carers are hurt by the attitudes of nurses. This group of children gets ill more frequently, and often get quite critical. The mothers explain how the local dispensaries and district hospitals do not feel capable of treating their children, and refer them to the national hospital. At the national hospital they meet the negative attitudes of some of the staff, who feel that they are abusing the system by going straight to the national hospital. They refuse to admit the child. Some professionals also show the mothers an attitude of 'why bother with children like these'. To keep fighting for the right of their children to health care is a tough job in itself.

"I remember there was a time he was sick ... It was around 8 pm. Reaching Muhimbili the nurses started quarrelling with me about why I had brought the child at that time. She told me 'you mamas have a problem: whenever you feel your child is sick you normally run to Muhimbili'. ... We all came to a state of misunderstanding each other, so I left immediately ... While I was running out, by good luck I met the doctor, and he

asked me why I was running away. I told him my child was sick but they do not want to accept her. He asked me what the problem was and I told him he had fever. I explained to him the whole process from a dispensary then to a government district hospital and lastly here at Muhimbili, but that I was wondering why the nurse refused to admit my child. So the doctor started the treatment there and then and he took him to the ward where he did not even stay long. He was taken to ICU as he was unable to breathe." Parent of child 3

4.2.7 Summary, group 1

Having a severely disabled child is very stressful. The carers love their special child a lot, but they are crying out for support. Exercises are the treatment for children who are not able to walk. Carers have seen it work for other children and want it to work for theirs, but despite many years of doing exercises, progress has been minimal. Carers find it difficult to carry out the exercises since they are painful for the child; therefore carers do not always do the exercises.

The disabled child is more prone to illness, which causes reduction of function. The one thing that gives the carers hope is the exercises, and this is then just the one thing they are not able to do. However, not doing the exercises also enables the carers to continue hoping "If I did more exercises maybe than my child would improve". They acknowledge that this might be a false hope, because it is unlikely that these children will suddenly improve. Having this hope gives the carer the strength to carry on.

There is a lack of suitable equipment and the carers find it difficult to find the money to contribute towards the equipment when it is available. It is especially difficult since most of them are unable to earn, since their entire time is taken up in caring for the child.

The children are very dependent on their mothers for all of their care. Feeding is a key activity which gives the children time to interact with their mothers; but which also causes the mothers stress when the child refuses to eat.

The minimal development of the child also causes further strain on the relationships of the carers. Mothers explain how relatives on the fathers' side blame them for having a disabled child and for 'putting shame on the family', and want the father to leave. One father, however, tells a different story of a caring sister and stepmother. For many families having a severely disabled child changes their relationship to their extended families. Mothers get more support from their side of the family, which seems more accepting.

An important source of support is religion. Carers are in need of hope. They even go to prayer services of a different denomination, hoping for improvement or cure for their child.

Many of the families live in poverty, which is exacerbated because most of the mothers are not able to contribute to family income. They feel that they are not able to leave their child with somebody else. The mothers' lives have become very isolated, and their own development is put on hold. They feel they need to keep up their spirits, because if they give up, what then?

The love of these carers for their children was expressed by one as follows:

"We cannot know what will happen in the future. Nevertheless, we just have hope that maybe maybe ..." Parent of child 4

University of Cape Town

4.3 Group 2: Children with cerebral palsy who are able to walk but also have an intellectual disability

This group of children has cerebral palsy together with intellectual disability. All are able to walk. Four carers were interviewed. All of the children have hemiplegia; however, in some of them this is only mild. All have a moderate to severe intellectual disability. Two of them also have epilepsy. Demographic information is provided in Table 4.2.

According to the carers, all of these children were born healthy - they were just regular children playing with others.

"X was born well, I mean so well. He was just healthy and he used even to play football." Parent of child 4

At a certain age they all got convulsions, probably due to high fever, and suddenly became disabled.

"She had become unconscious and had paralysed the whole body so she got pipes in the nose, which were used to feed her. After going home, we used to force her to eat and thereafter we trained her to sit down." Parent of child 2

"By the time she was waking up, her limbs were no longer functioning and the neck also became so weak." Grandmother of child 1

Table 4.2. Demographic information, group 2

	Participant carer	Age	Sex	Impairment	Ability	Onset of impairment	Social situation
Child 1	Grandmother	6 years	F	CP hemi + intellectually disabled	Walking, problems talking – not started kindergarten	Became disabled at 1.7 yrs after high fever	Father did not want to marry the mother; carers very young. Grandmother raising the child
Child 2	Mother	9 years	F	CP hemi + intellectually disabled	Walking and talking – going to school. Standard 1 for the second time	Became disabled at age 4	Not sure how mother gets her income. No husband, one older brother
Child 3	Mother	8 years	M	CP hemi + intellectually disabled + epilepsy	Walking, problems talking. Going to school, Standard 2	Became disabled at age 4	Child lives with parents and has one younger sibling
Child 4	Father and mother	8 years	M	CP hemi (mild) + intellectually disabled + epilepsy	Walking, problems talking. Not going to school.	Became disabled at age 4	Last born of seven children; interviewed at home

CP hemi = cerebral palsy hemiplegia.

4.3.1 Physical well-being

4.3.1.1 Cause of the impairment

People believe in a medical cause and accept modern medicine. However, one carer also believes in witchcraft and spirits and looks for alternative treatments. Carers will try out different things at the same time. Exercises are seen as modern treatment.

"Because that illness of convulsions is well understood by many and they know that, it attacks children and the effects. Even when I first went to hospital, we were many of us with such problems. ... and I advise them to take their children for exercises but some are thick to understand." Grandmother of child 1

"So we did our own traditional things and sacrifices and by good luck the neck became strong and stable. He was not also able to sit as the whole body was weak; we did the same traditional things and he began sitting. When the time came for going to take the medicine we went and he started using that medicine. ... But the condition did not change to the better ... While doing all this [traditional way of healing] we were still in your hands, but were also trying out some other ways." Father of child 4

This carer does not want to accept that his child is epileptic, and has his own theory which explains his child's condition:

"He still uses medicine. We are given it at Muhimbili. For his disease I don't understand what is wrong with him because I am not a specialist. The doctor in charge gives us the medicine. If he does not use the medicine, he increases the running. ... He used to convulse in the past but nowadays he does not." Father of Child 4

4.3.1.2 Epilepsy treatment

Carers obtain treatment for their child's epilepsy at different hospitals with varying results. They end up going to several places to get treatment and receive different advice at each place. One carer's child was treated at Muhimbili, the national hospital, and prefers CCBRT. Another parent was at CCBRT and prefers Muhimbili. Carers will remain with the facility from which they see the most benefit.

"We were then referred to Muhimbili [by CCBRT]. When the doctor saw the child he was so annoyed and said that the child was neither psychiatric nor mentally retarded. They told us to show them the medicine he was using and he said that it was the medicine which was causing all those problems. Therefore he prescribed another type of medicine." Father of child 4

"So than I went to CCBRT hospital (after receiving treatment at Muhimbili) and they told me to stop using the medicine I had been given earlier at Muhimbili as they claimed they will not help him in any way. They wrote for me some other medicine which he is using until today. They told me the medicine is to prevent him from convulsing. In addition, it is true as since he started using that medicine he has never convulsed again until today, and I have even forgotten that my child has that problem." Parent of child 3

One mother appreciates that now she is able to get a two month supply of medication because visits to collect it used to collide with trips to the clinic for exercises.

"I still take [the medication] and now they arranged to collect it every two months. We used to go every monthI think it is okay because the dates for taking the medicine used to collide with the same date of going for exercise, so when they changed to that you can at least find that you go for exercises like on a Monday and then you go to take the medicine on a Wednesday." Parent of child 3

4.3.1.3 Physical exercises are not enough

Physical exercises are seen as very important, and the carers believe exercise to be the one main treatment that can improve their child. Carers think that when the child is able to walk and talk then overall they will be well.

"I did not expect at all that she would be able to sit nor walk. All I knew was that she would sit down for the rest of her life as she sat down for a whole year and she could not do anything - even if she falls down she could not lift herself up. However, after taking her for the exercises she started doing well until she reached a point of walking. ... Her body is strong." Grandmother of child 1

Carers come to realise that even if their child has learned to walk, they are still not able to do all activities. One mother stopped seeing the point of going for exercises since they were only stretching the child and not doing anything to increase functional abilities.

"She attends the local clinic and this is where she got an improvement ... She got exercises. They stretch her. The improvement is that she can now walk - there is nothing else ... She can also go to the toilet. They stretch her at the exercises. If there is any help it would be good as there they only stretch her... There is not that much of an improvement. When I get bus fare I go to the exercises ... I don't give her exercises. I normally walk her around." Parent of child 2

4.3.1.4 Importance of being able to communicate and behave

Communication is still a major problem for three of the children. Carers believe that this reduces the child's opportunities. Carers explained that their children are able to understand but are not able to talk. They have received some advice but this has only led to the children being able to say some basic words such as 'mama' and 'baba' (father).

"I used to take her there while she is walking until they get surprised, so they told me to struggle so much to be talking to her by telling her bring this or that, she will understand what you are saying even though she will not be able to speak, but she will understand what you are saying. So right now this child understands but she cannot talk. She is now beginning. She can speak some words but others she cannot." Grandmother of child 1

"The problem I am facing right now is that he does not know how to talk. He can only pronounce two letters, but if you join then he is unable to pronounce. He can only pronounce short words like baba, mama, dada." Parent of child 3

Together with limited speech come behavioural problems, which carers find even harder to cope with. One child keeps running off. Out of desperation, these carers often keep this child in the bedroom. They started giving responsibility to the rehabilitation worker, calling it her child - probably because they have given up and do not know what to do anymore.

"I thank God because we are always together with this lady from CCBRT She keeps on coming to check the child. She keeps on coming here to see her child and it has helped because he never used to talk but he can now call dad and mum and even sing some of the songs he knows, but he does not pronounce the words clearly. Our main problem now is about his talking and running. If he starts running here you have to work in order to catch him." Father of child 4

4.3.2 Emotional well-being

4.3.2.1 Concern about the future – afraid to acknowledge the child's learning difficulties

Carers are worried about the future and insecure about the abilities of their children. In the first instance they blame the inabilities of their children on their physical impairment, and only later acknowledge the learning difficulty.

"I don't know how she will be in future. I think she will only be able to do activities if her hand will be treated. Until she recovers ... She has learned a few things.... Maybe if she stays with other children and specialists she might improve a bit education-wise. And maybe also how to hold a pencil because where she is they just support her." Parent of child 2

Interviewer: *"I can see that she has no problem in holding the pen."*

"So will she understand?" Parent of child 2

Carers worry that not being able to speak will limit the opportunities of the child to be able to function, and they are especially worried about whether their child will be able to do well in school. Carers seem unaware of how the intellectual impairment impacts on the communication abilities of their child, and seem to blame the inability of their child to learn on their lack of speech.

"It is my wish that if God helps him, he should be able to talk. That is what I am crying for. ... When I go for the exercises they told me to put honey on the upper lip so that he can stretch out the tongue to lick it as it will assist him to be able to pronounce words." ... "I think if he will be able to speak it will even assist him in his education. Because right now he is schooling but he just hears his friends speaking so you find that he also wants to say the same thing but he is unable. That contributes to him remaining behind in terms of education, and as you know if you are not educated you are so much behind." Parent of child 3

4.3.2.2 Friendship and play

Three of the children are happy and have a lot of friends.

"He has so many friends. Even if he is sick, they normally come here and ask where is X, so I tell them he is not feeling well. His friends just come and tell him let's go and play, or he goes to the others. He calls them 'kaka'. He just calls them kaka even if he is playing." Parent of child 3

One boy spends a great deal of time in his room. Every time he gets a chance, he tries to run away. His carers are worried and cannot see a way to change things. His actions only further confirm that things are hopeless, which makes them more determined to keep him inside.

"When he is tired, he can get inside and sleep, as he is normally tired. If you send him to bring you something, he goes. However, he does not understand enough to come back home. He can run up to the road. He can even board a vehicle, and he has no brains to remind him where he came from and where to go next. You as the parent have to be so alert." Mother of child 4

4.3.3 Spiritual Well-being

4.3.3.1 Participation in religious services

One of the children participates in religious services. He started going to a Christian church together with his friends even though his carers are Muslim. He enjoys going to church.

"I am a Muslim, but surprisingly my child likes going to church. It is because his friends go to church and there used to be a woman here who was saved, and she really liked going to church. So every time she went she used to call X to escort her. I think that is what made him know that there is something like that. There is also a church just near here. Immediately he hears them singing he says 'mum I am going to church', so I find it difficult to stop him as it is not good to do so. ... He will know where to go when he grows up. But he will know that he is a Muslim. For now, I think he has not understood yet. He just knows as long as I am on earth, God is God." Parent of child 3

The other carers are not taking their children to religious services. They give different reasons for this, such as their child not understanding, incontinence, and behavioural problems.

"Her father is a Muslim and the mother is a Christian. ... She doesn't know how to pray. I am afraid that when she goes to the mosque she can urinate on herself. And even if she goes she won't be calm. She will be playing." Grandmother of child 1

The religious institutions offer varying support; one Sheikh even makes home visits, while at another mosque they do not even know the child exists.

"No, I have not taken him to the mosque, but our Sheikh normally comes here to comfort us, or he can even send the elders and the youth to come and see us." Father of child 4

"I am a Muslim. I go to the mosque on Fridays. The mosque people, they are of no help. The children, there are times they go and others they don't. X, she does not go because of her condition. They don't even know that she exists." Parent of child 2

4.3.4 Personal development and material well-being

4.3.4.1 Reduced self-care and household activities

All the children have reduced abilities to look after themselves and to take part in household activities. Carers mention especially incontinence as a problem; they are at a loss as to how to educate their children to become continent and to use the toilet.

"There is one thing that is really giving her a problem. She cannot go to the toilet. She is able to say 'I want to help myself'. She sometimes helps herself in the clothes. She can show by folding her dress. When she folds her dress or she can remove her panty but then she cannot put it on again." Grandmother of child 1

"... he cannot even say when he wants to help himself so we are forced to suffer because of him. Because he does not talk, he is even unable to go to the toilet. He has no sign." Father of child 4

All carers still help their children to wash themselves to different degrees; they do not think their children are able to wash themselves properly and feel they should do it for them. It is very important for carers that their children look clean, so even the children who are able to go to school are washed.

"She cannot wash herself. She can wash her hands when it is time for eating, but it is like just playing with water. If the dress is wide, she can remove it." Grandmother of child 1

"If you tell him to wash, he can scrub himself using the left hand as it can even carry a gallon of water. He can scrub but then as a parent you feel like he is not clean so you wash him again and rinse him with clean water. He can dress." Parent of child 3

Generally non-disabled children are expected to participate in household activities. Carers differentiate the children: they have not started to train the disabled children and regard them as just playing because they are disabled. Carers do not perceive that stimulating their child by doing activities could be a way to develop their child.

"To sweep and things like that, she does it, like just playing but not really sweeping so keenly. I haven't started training her. Right now it is like she is playing. Whatever she sees happening she also tries to do it. Even when you are washing her, after applying her with soap she cleans herself and rinses herself with water." Grandmother of child 1

"I would like her to help me, but if it is possible the leg should either be operated or she should be given a shoe so that you can help her. I have not yet taught her small chores but I will teach her because even when I give her the socks to wash she can do it. I am trying to teach her slowly by slowly. Also her hand..." Parent of child 2

4.3.4.2 Poverty of the family

Bringing up a child with a disability is costly. This is difficult for families who are poor and have no financial reserves. One father complained about all the costs, and especially the cost of epileptic drugs. The father is retired and they totally depend on a little bit of rent they get from renting out their small house as a shop. They squat in a very old estate house which has not been maintained for many years.

"This child is so demanding as he needs money for treatment, yet I have no money. If you take tea today, you have to wait for three more days in order to take tea again. Life is hard and I have grown older. By good luck, I have a small shop, which supports us in our daily bread. We have just rented this house here. It is to support us in eating. The shop itself is not so good. Father of child 4

One grandmother explains how her daughter-in-law left her child with her. The daughter-in-law was very young, but this was also to a large extent due to lack of finances.

"She does not get along with the husband, but with me we really get on. ... She really loves the child and she does not have any good job but she just does some small businesses. So I looked at that situation and said if I leave the child with her, it will create another problem. I listened to her and I understood her because she is also just there. It is possible that she can even lack the money to prepare food for the child. So the child is here with me, but the mother comes to visit her." Grandmother of child 1

4.3.4.3 Employment or lack of it

One carer explained that she had never worked because her son was too disabled to leave with anybody; another explained that now that her grandchild had improved she was able to do some small business again:

"To be sincere, I have never done any business because of his condition. If I leave him to go and do business, I will be worried all the time as I am always with him. Whenever I go I must go with him and wherever I travel then I also have to go with him." Mother of child 4

"I was unable to do any kind of business ... because of this child. The way she is now [meaning improved], I can do my own work. Grandmother of child 1

4.3.4.4 Expecting charity because of having a disabled child

With some carers it was not clear how they made a living - they seem to depend on hand-outs of others. Having a disabled child also provided an opportunity to ask for help due to the general attitude that PWDs need charity.

"I just struggle but I don't even have a business. I don't have money and I also don't have any business. I also don't do day labouring. I just take this one to school in the morning. ... I don't have anyone [meaning a partner or close relative]. I just struggle

4.3.5.2 Effect on siblings

Siblings love each other but can also tease each other. One disabled child will let his younger brother do so up to a certain extent, after which he will stand his ground and make it clear to the sibling that he/she has gone too far.

"He is the first-born and he has a follower who is 3 years old ... They get on well and this one favours the younger brother so much. The younger one is so naughty. ... This one can tell him something but then he does not talk well so the younger one starts abusing him 'why can't you talk properly?'. It is because the older one does not talk. He just laughs the way he is laughing and says you; if I beat you I will hurt you." Parent of child 3

4.3.5.3 Effect on partnership

Partners can be very supportive, and can encourage each other.

"The father takes him the way he is, we cooperate with each other, and he is even the one who encourages me. If I tell him there is a problem which has arisen, he tells me to follow it and in case he does not have money, he tells me to borrow from someone, then he pays it later." Parent of child 3

Another couple separated, but this was not due to the disability of the child. They were very young and had only just finished school. Mother and grandmother decided that it was better if the child stayed with the grandmother, but the mother still is very dedicated to her child.

"The father, my son, has finished school but he is just at home. If at all he still had his own work, I could advise him to remain with the mother of the child, but now even I myself when I look I see he is not able to live with a wife. But the mother comes here to visit her child very well, she even brings her presents. She used to even bring flour, milk, soap and everything." Grandmother of child 1

One mother was left by her husband when the child was four months old. The mother remarried but was left by her second husband as well. The second husband has since died.

"Their father is not around. For this child I just became pregnant with him and he deserted me when she was 4 months old. Since then I have no one to assist me with anything. This younger boy has a different dad. His dad left me when I was 4 months pregnant. He has died now." Parent of child 2

4.3.5.4 Effect on relationship with relatives and neighbours

Three of the families get on well with their neighbours, but one family with a child who has also severe behavioural problems does not get on with the neighbours. They feel that you cannot expect relatives to help with such a child.

"They accept him and I am grateful for that. Even if he does something wrong someone comes to report him at home, but they do not just beat him up. They understand his condition." Parent of child 3

"The neighbours don't say anything. Some dislike him coming because you can find someone has made her house so neatly, but he goes inside and dismantles everything. So I find some gets so much annoyed and do not understand that this child has a problem. So it is on you as the parent to go and ask for forgiveness and say that he has a problem. If the person understands, she will tell you it is okay." Mother of child 4

4.3.6 Right to education

4.3.6.1 Being at school

Two of the children attend regular primary schools. They needed to get used to school, and the other children needed to get used to them. One boy still gets distracted on the road, which delays him.

"In the past she used to refuse to go to school because others used to follow her so much and even laugh at her. But right now she is used to them." Parent of child 2

"He used to go by himself to school but when he meets someone on the way he stops and they start talking so the teacher talked to me about that and we agreed that I will be taking him to school by myself, and then he comes back home by himself. That is why he comes back here at 4:30 instead of 4 or at 4 instead of 3:30 – in case anyone calls him on the way; he will stand and talk then spend a lot of time before he continues going home." Parent of child 3

4.3.6.2 Not sure which type of education is best

Carers are not sure which type of education is best for their child. Two of the carers, through education of the programme staff, have started taking their children to a regular school. The carers themselves found a local primary school which accepted their children. One carer acknowledges the benefit of the regular school, but blames the child's inability to write on physical problems.

"I tried to look for a boarding school for him to learn but they told me that he is not supposed to go to boarding school as I am supposed to be close to him. They told me to take him to a neighbouring school. Therefore, the father went to talk to teachers, they allowed him to join the school, and he is now in standard two. When it comes to writing, he uses the left hand as the right-hand side is paralysed. Therefore, because of using the left hand, to write a number like 2 becomes a problem. He can write 'o'." Parent of child 3

The carer of the other child finds that her child is not learning at the regular school; teachers have no time for her child, and she wonders if her child would learn more at a special school. In general the carers seem to be very insecure regarding what is available and the potential of their child to learn.

"I think she will take time to learn. Or is there any possibility somewhere else? She is now at a regular primary school. The teachers do not really follow her up. They just teach her as a normal child. She does not know how to read. Last year she started

standard one but she did not understand anything so they had to let her repeat the same class. This year she was supposed to be in standard two but she is in standard one. She has not started understanding very well. She has learned very little." Parent of child 2

One child is not used to sitting with others and has behavioural and continence problems; therefore his carers are not sure if there is a school that would take care of their child.

"Our reason for not taking him to school is because of the way he runs at random and he helps himself. Which teacher will be able to look after him? I have no ability of taking him to the special people so I am just here with him. ... You are our leaders. So you can tell us where you think is appropriate, as you see much beyond than we do." Father of child 4

4.3.6.3 Assistants/helpers

One child has a helper/assistant from CCBRT at school. It is not clear from the carers when a child gets a helper and what the role of the helper is. The helper writes in the exercise book on behalf of the child, but it does not seem to be part of a particular rehabilitation strategy. It puts the carer at ease to know that there is a helper for their child in the class.

"She has her assistant. A lady from CCBRT, she normally helps her. I think it is good as even the child gets the heart of staying with other children without fear. She sits with her in class. The helper must support her hand, as she cannot hold the pencil nicely. ... I think I should show you her books." [Girl herself shows her exercise book says that the helper holds her hand – very mature drawing and writing in the exercise book].
Interviewer: *"Can you write?"* The girl starts drawing, saying "This is how I write". She was able to hold her pen well and draw/write scribbles, but could not write her name.
Girl: *"I have written sums."* Interviewer: *"What have you written here?"* The child had written a zero.
Child 2

4.3.7 Summary, group 2

These children are all able to walk independently, and the main issue is their learning disability. Some carers still focus on the physical problems of their child. They hope that when the physical impairment is reduced, the child will generally improve. Some carers have seen that physical exercises no longer do much for their child, and are looking for advice as to what else they can do to improve the functioning of their child. Most children have difficulties with communication, and apart from a few ideas the carers do not really seem to understand how they can stimulate their child further.

One family does not believe that their child is able to improve. The child uses anti-epileptic medication, but they do not really acknowledge that he is still epileptic. They have tried both traditional and modern treatment but the boy has not been 'cured', and

they now seem to have given up. The boy is kept in his room a lot and has many behavioural problems. The carers feel that they deserve charity and should be helped more.

The other carers see their children quite differently. The children are integrated in the neighbourhood and have many friends. The carers see that their children are able to do certain activities; however, they are not clear about whether and how much their children will be able to learn. They do not realise that teaching their children daily life activities stimulates their general development.

The carers are worried about the future. This comes out when they make comments such as 'he just plays all the time'. They cannot see how they can get their child to participate in the chores and obligations of the family. These carers could benefit from education about how they could assist in the cognitive development of their children, which would improve their general functioning and communication abilities.

Education is seen as very important, and carers are confused about where to send their child for education. The two children in school are at a regular school. They are not learning, but carers are not sure if they would learn more at a special school. The role of the helpers seems to be unclear with these children, since they do not need physical support. Having educational support in class could be very useful for these children if the assistants followed a rehabilitation plan. Ideally, this should be part of the general rehabilitation plan of the children.

Only one child participates in religious activities. He goes to church instead of the mosque, since this is where all his friends go. The other children are not taken to religious activities because of their impairment.

4.4 Group 3: Children with cerebral palsy and a physical impairment who are able to walk

This group of children has cerebral palsy but are able to walk. The carers of four children were interviewed. Two of the children were also interviewed by themselves. The findings from the carers and the children themselves are presented separately.

The children have either hemiplegia or diplegia. One also has epilepsy. Although all of the children are able to walk, one uses crutches and the two girls who have hemiplegia, walk with a limp. Demographic information is provided in Table 4.3. Two became disabled almost straight after birth, and two became disabled later.

"He grew up very well until the age of 9 months when he had started standing by supporting himself on objects. Suddenly he was attacked by convulsions. After that he became so weak. So we took him to Ndanda hospital where he was treated, but then he stopped talking and he started drooling. He used to stand but he stopped and became someone who just slept throughout. We struggled with him but then he was really behind. He even became like mentally retarded. I just continued taking care of him and taking him to hospital for medication but then he was not talking." Parent of child 4

Table 4.3 Demographic information, carers in group 3

	Participant Carer	Age	Sex	impairment	Ability	Onset of impairment	Social situation
Child 1	Mother	3 yrs	F	CP diplegia	Starting to walk with more balance, able to talk	Had malaria 3 days after birth. Mother noticed at 6 months that child had delayed development. Only started exercises at age one and half	Lives with her carers and her twin sister. Father has his own business, mother stopped working
Child 2	Mother	7 yrs	F	CP hemiplegia	Is able to walk with a limp, able to talk. Weakness in one hand. Stopped going to kindergarten due to social problems	Was born legs first, delayed crying, got 10 injections. Mother noticed after several months that the child was delayed in sitting	Lives with carers and is one of two children. Father is a cook, mother housewife. Father just sold the house they owned. Now they rent a room
Child 4	Grandmother	13 yrs	M	CP diplegia	Able to walk with crutches, able to talk. Going to school, Standard 4	At age of 9 months, started to have bad fits, after which he stopped talking and standing	Lives with grandmother – have a nice house. Grandmother does not indicate how she gets her income
Child 5	Father	15 yrs	F	CP hemiplegia + learning difficulty + epilepsy	Able to walk, able to talk. Going to school, Standard 6	At age of 4 she got cerebral malaria and was unconscious for some days. After this she became disabled	Lives with carers. Mother owns a shop. Father farms and does some business and is the main carer. She is one of several children

CP = cerebral palsy.

Results of interviews with carers, group 3

4.4.1 Physical well-being

4.4.1.1 Importance of exercises

Physical exercises have improved function and give hope for a better future for the children. Carers actively participate in the physical exercises, trying to obtain increased mobility.

"So I continued going for the exercises and each time they did the exercise, I could come back home and do the same exercise to the child until I saw the child's condition becoming better, because when she begun crawling, she used to crawl on her stomach like a snake then after sometime she started crawling and eventually started walking. I had lost hope before I started, but after going there for sure I didn't give up again. I used to encourage myself and it is true and I am grateful that my child now walks."
Parent of child 1

Carers will go to more than one place or even to more than one clinic of CCBRT, thinking the more exercises the more improvement. Carers compare services. Some carers try out different places for exercises and remain with the one they think is best. They praise CCBRT for their quality of service.

"I truly believe that exercises are important. ... There are so many of them I was with, and some tell you I have gone to 'mama cheza' (at Muhimbili) for quite long but I have not seen any change, but at CCBRT I think they have seen the change." Parent of child 1

"We were doing the exercises at Muhimbili but then that became an issue. When you go to Muhimbili it is a long way and when you reach there they do the exercise for 5 minutes, then you are given another date to go back." Parent of child 5

4.4.1.2 Exercises not solving everything

As the children are walking, carers find that exercises are no longer the main priority for their child. They realise that other things, such as education, are now more important for the development of their child.

"Eventually here I am now not very healthy. I cannot carry him to the exercises and at the same time, he is needed at school so I stopped going. He just goes to school."
Grandmother of child 4

Carers do expect more and other services than just the exercises. They would like support with other issues, especially when the child is still not 'cured' and has other problems.

"After the exercises, she started improving in sitting, standing and walking. I received just the exercises for stretching her limbs. Now I do not receive any services." Parent of child 2

One father expected a cure; he focuses on his child's impairment, which is obvious to see as she still walks with a limp and has a flexed arm and hand. His daughter is able to do a lot of things, but he would like to see his daughter doing things normally using both hands. He still thinks that maybe with more or different exercises there might be more improvement and even a cure.

*"The hand prevents her from working well. I don't know if you understand me. She uses just one hand, the other hand is just there. It is not that she is unable, but the work that she should have used both hands you find she uses only one hand." ...
"What I am saying is I would like to see some improvement of her limbs to the extent that she is able to do something with them that is an improvement. In my case for sure I don't see any change." Parent of child 5*

4.4.1.3 Health concerns

Carers have diverse concerns with regard to the health of their children, and wonder if there is something else wrong with their child. One mother thinks her child might be epileptic and is very concerned about this. She feels that her child has not been assessed properly.

"I think it is epilepsy because every month she has to get the attack. What kind of malaria is that? She is usually without any fever. She just convulses suddenly." Parent of child 2

One other girl has improved health and function due to availability of epileptic medication at an affordable price at CCBRT. Before, they struggled for years to obtain drugs. At some stage she had no more seizures, but her parents had to stop giving her medication because they were not able to afford it. After stopping the medication, the seizures started again.

"When she gets the medicine at the appropriate time, she does not get the epilepsy attacks. Till now it is like one year she has not convulsed. We used to buy the medication in shops ... and we think there is one good thing with CCBRT because it is a drug of the same type all through. In the shops today you get those ones from India, tomorrow from Syria and the other day from another different country, so we end up not knowing which out of those is the best, and how it works on the patient." Parent of child 5

4.4.2 Emotional well-being

4.4.2.1 Being treated differently

Children want to be like other children; they do not want to stick out, and will try very hard to manage things.

"At first I used to carry her taking her to school, but she used to cry she wants to go by herself. She used to say she wants to go alone. So there is a day I carried her to school and she cried so much so I left her at school, but surprisingly she came back home by herself." Parent of child 2

However, they are often viewed as different, which is hard for the children to realise. Over time the children learn to cope with this and it becomes less of an issue. The people around them get used to them, and they know how to deal with new people.

"They used to fear him but now they are used to him. He used to feel shy at school during the first days. He would wait for all the pupils to leave before he picked up his crutches to start walking home. Why? He says 'I feel shy when I walk, they laugh at me'. I would tell him you just thank God. But right now they are used to him." Grandmother of child 4

Carers try to advise their children about how to deal with this.

"Because she is disabled, people used to call her funny names, so she would always come home crying, but right now I think she has become used to it and she knows it is her problem. They will talk but at the end, they will finish. Right now it is not a major problem. I have tried to talk to her by telling her that you cannot stop someone from talking because the problem is not with him or her." Parent of child 5

Carers feel hurt because of the way their child is treated by others. One father explained how his daughter would even question why God had done this to her.

"Okay I am grateful that these days she has no problem. But in the past actually even I myself felt so hurt because she knows that she was very well at first but now she is disabled. So anything that happens contrary to her, she says okay. I know you are doing this to me because I am disabled. This really disturbed me, but nowadays it is no longer a problem." Parent of child 5

Carers have to deal with the attitudes of neighbours and relatives who believe that the impairment was caused by Satan, that it is a curse, and that the child will not improve unless the curse is removed. This is difficult for carers, but they do not want to believe it and look for their own ways to keep up hope.

"The relatives did not know the cause. They just used to say it is Satan who caused all that." Parent of child 2

"There are a lot of things they said, because when you stay with people some say it is witchcraft, but I never lost hope because I was directed to go to very different and strange places or to witchdoctors but my spirit was reluctant to work on that. What I did was just to pray to God to help her as I continued going for the exercises." Parent of child 1

4.4.3 Spiritual well-being

4.4.3.1 Hope and support through belief in God

Children and carers get hope and support through their belief in God. The children themselves are active church members and feel supported through the church. One child goes to a different denomination from his carers.

"The church helped us. People of God have been praying and we have been praying together. She likes church a lot. They involve her well in all church activities and even singing." Parent of child 5

"There is a church near here where he goes but I go to another church, which is very far from here. He really likes going for prayers." Grandmother of child 4

Children and carers feel challenged in their faith by questioning why they are disabled and why God is not healing them.

"And sometimes I could pray for her and she could later on ask me why can't this God heal me? Of course that is a very challenging question on my faith and I cannot give her a straight answer, but I could explain to her to my level best, but right now it is not an issue." Parent of child 5

4.4.4 Personal development

4.4.4.1 Increased activity level - independence

Carers explain that their children are able to do more and that they have increased their functioning and independence.

"If you give her tea she now drinks it as usual. She just eats well. In case she wants to help herself she asks and I take her. After she was able to walk, she started to learn how to talk. I think she is even better in some words than the other twin is." Parent of child 1

Carers stimulate their children to participate in the household activities and so that they are active.

"I normally send him to the shop because when he comes back I tell him not to use the crutches, but then he walks like a drunkard so you have to send him only the light things. I give him a basin with water and his clothes and tell him to sit and wash them and indeed, he washes. Even when we have finished eating, I tell him to pick all the utensils from the table and he tries. I do not just leave him that way, but I tell him to do something." Grandmother of child 4

However, two of the carers keep seeing the impairment, and find it difficult to see that even though the body functions differently, the children still have a lot of abilities. Carers do not seem to understand the benefit of teaching their children activities. This

results in carers who continue to look at how to improve body function for many years, instead of looking at the individual abilities of their child and what to do with those.

"She can fetch water, wash clothes; actually my daughter is really hard working. It is just bad luck; I am regretting that she became disabled. She does what she can." Parent of child 5

"She can wash her hands but then she uses one hand. The right hand is not strong. She even writes with the left hand." Parent of child 2

4.4.4.2 Future expectations

One father has been focused on a cure for so long that he has not thought about the future of his daughter yet. Looking realistically at her future would require the father to accept that her body might not improve much more. During the interview he acknowledged some of her abilities, and in the discussion started contemplating what would be realistic and what she would be able to do. He was clearly looking for more advice.

"Her future - that is what is troubling my head. Of course, she has some good things in her that my other children don't have. ... She can make friends without any problem unless just someone rejects her. She is quite different from other children I have. The others are so thick. ... For instance, when the lady from CCBRT came here for the first time, she quickly introduced her to some other children who are also like her. This is not something easy for another person to do, but she has no problem. Even when I come back here at home, she comes and welcomes you in the house, but for my other children I must even greet them and ask them how they have been." Parent of child 5

One grandmother believes her grandson will go on to secondary school even though it will cost her a lot of money. She is convinced that a good education is important for a child, especially if he is disabled.

"I really wished that he goes up to secondary school. He likes things to do with computer. He even says that I have no legs but I really wish to do something on the computer. I cannot say if he will qualify for secondary school or not but it is my wish that even if he does not qualify, if I have the potential I would take him to an expensive school." Grandmother of child 4

4.4.4.3 Personal development of mother varies

One mother stopped doing business because of having a child with a disability. She wants to start up some business again when the child has become more independent, because she said she could not continue to depend on her husband.

"I am just at home because these children are still young and for instance this other one was not quite well, so I could not do any business or work because I have no one to leave him with. My husband does business. The business is his. I have that plan to start something again because I cannot just say that I sit and depend on him." Parent of child 1

In another family, the mother has her own business and seems to be the main breadwinner. Here the father takes a more caring role.

"Her mother is not around right now. She owns a stationery shop, which is where she is. Most of the time she works; you know the self-employed jobs are so demanding." Parent of child 5

4.4.4.4 Material well-being

Carers say it is more expensive to care for a child with a physical impairment. One father explained that he was not able to afford to pay for his child's epilepsy medication before CCBRT, but that now he is managing due to the reduced costs.

"There is a time the price went so high, but I was working for some Indians who were really helping us, that is in the 1996/1997. That was the first time she stayed for long without convulsing. Afterwards the job ended we faced the same problem again. ... At CCBRT we just contribute some amount. For example, I contribute 5000/= every time I go to take medicine. It is not big as compared to buying one tablet at the shop." Parent of child 5

Two of the carers also seem to use the impairment of their child as a way to ask for support or money from others. It is not clear how some carers earn a living. They feel that a person with a disability should receive material help, and that the programme should help more with paying for equipment. One of these carers manages to send her grandchild to a private primary school.

"But his crutches have become short as he has grown tall. I am supposed to make others for him. His shoes get worn out so fast. ... He should be given clothes even just for luxury provided he wears them because you know when a disabled child sees he is different from others, it makes him feel bad. It is important that he wears shoes and socks like the rest. That way he feels he is on the same level as others. I just want to say that people like us should be helped in case there is any aid for disabled people like him." ... "I am the one who pays his school fees and that is why I didn't take him to these public schools. I took him to an expensive school. I pay sh. 150,000 for him. I was told that in July I am supposed to pay sh. 73,000 for food as they want to start cooking for them lunch at school. I have also enrolled him for tuition where I pay sh. 1,000 every month." Grandmother of child 4 (focus group)

4.4.5 Social well-being

4.4.5.1 Effect on siblings

Siblings are supportive of each other. One sibling supported her sister to go places and she likes to help her.

"When she started walking, the other one could make sure she holds her hand and wherever she goes they went together." Parent of child 1

4.4.5.2 Importance of friends

The children have friends and are included. The children enjoy being with other children, and even though they cannot walk they try to follow them. When they meet new children they need time to adjust to each other.

"They are used to him, they no longer get surprised - they even come to visit him. He even borrows 50 sh to go and watch TV and when I give it to him he goes."

Grandmother of child 4

4.4.5.3 Effect on partnership

In some families it is the mother who does the main caring for the child.

"The father also did not lose hope. He was on frontline to encourage me to continue taking her for the exercises, because the more I continued going you could see that when we are seated you could see some changes in the child." Parent of child 1

"I am the one who struggles with her. For sure I have never seen him [husband] taking her anywhere. He gives me bus fare, he leaves me money, but he likes her more than the other child." Parent of child 2

In one family, however, the father is doing a lot of the caring because the mother runs a shop. They have a good relationship and share some of the responsibilities.

"Her mother is not around right now. She owns a stationery shop, which is where she is. Most of the time she is at work. You know the self-employed jobs are so demanding. You can't get a chance not to be around because being there means you have worked. She is not free most of the time. But I think tomorrow or the following day she will go to CCBRT to take medicine. That is how we had planned." Parent of child 5

4.4.5.4 Difficult family circumstances

Some families live in difficult circumstances. In the case of one mother the husband suddenly sold their house. This also meant that the children had to stop going to kindergarten.

"I just moved here recently. I have not even finished a month. Our old house was sold. He wants to look for another one at Chalambe. He is a cook in a hotel right in town. There is no proper reason why he sold the house." Parent of child 2

One grandmother brings up her disabled grandchild. He is her 'special grandchild' and she thinks she is the only one who can bring him up properly. She really sees him as being her responsibility, but she also sees herself as doing a charitable act.

"This is my grandchild. He is the son to my daughter. As you know women nowadays, they do not take good care of their children. ... I have four grandchildren to take care of but I have to give more care to this one because he is disabled, and so he is like my own child, but these other ones have their mothers." ... "People say they did not expect he would get well. They say it is good to have such a heart of taking care of children. So I am just taking care of him but life is so tough and he is disabled." Grandmother of child 4

4.4.6 Right to education

4.4.6.1 Importance of education

The importance of education was generally acknowledged by all carers, and they all looked at opportunities to send their child to school. The carers are aware of the strengths and weaknesses of their child at school and look at ways to improve their learning further. One carer sends her child to a private primary school because it is closer and he will get a better education.

"Nowadays he is okay as in the beginning his brain was not okay. He has repeated each class twice but nowadays he understands. He never used to understand anything. This year when they were being promoted to the next class [Standard 4], he was number 9 out of 20 children. He really struggles. The only subject that gives him problems is English." Grandmother of child 4

"She is getting on averagely. If she was scoring 15 marks, right now she can score 40." Parent of child 5

The grandmother realised that her child would not be able to reach school, so she made him a pair of crutches and taught him how to walk with them in order for him to get there.

"After my child became 8 years old, I was stranded on how to take him to school. So I went to a carpenter who made crutches for him for going to school. I taught him how to use them." Grandmother of child 4

4.4.6.2 Right to choose form of education

This group of children who are walking did not have a problem being accepted by a regular primary school. However, one father tried to enrol his daughter into a special school. He felt she would get better education there than at a regular school where the classes are big and the teachers do not have time to give individual attention to the children. However, the special school refused her. He feels that with specialist input she could have learned more. He feels powerless to do anything about it.

"We even tried to take her to Salvation Army to school there but they refused and said that it's like we hate her because why do we want her to go to school there. I said it is not that we hate, but we tried to almost two times then but they were not accepting her, then I said maybe God wants us to stay with our own child. So I said it's fine. ... The teachers just teach her like other children. They cannot consider a disabled child. For sure it is hard. It is something that even me myself I could not do because the class is big with many students. But I am sure that if there were specialists who know how to handle such children they could know of a better way of helping them than just a normal teacher. But for the time being, we have to accept whatever we have got." Parent of child 5

4.4.7 Summary, group 3 carers

This group of children with cerebral palsy is able to walk and has no intellectual disability. One girl also has epilepsy. They have all learnt to walk, although one boy still needs to use crutches. Unfortunately his crutches were far too short, but his grandmother said she had not been able to buy him others. By the focus group discussion she had managed to buy him longer ones, but confirmed that he had developed some contractures from walking bent for so long. The rehabilitation programme has never given support for obtaining walking or other equipment.

Carers all confirmed the importance of exercises and have seen a lot of improvement in the children over the years. Two of the carers stated that physically their children have reached a plateau. One carer still feels that his daughter could go further with exercises that are more regular and intensive. Because he is still looking for a cure he has not thought yet much about her future, although she is already fifteen years old.

The children had to adjust to being seen as disabled. This became especially clear with the two older children. Carers find it hard to deal with the hurt of the children. The children and carers get hope and support through their religion, but also ask why this happened to them.

Carers mention the extra costs involved in having a child with a disability. One carer appreciates the availability of epileptic drugs for a reduced price, but another mentioned having to buy equipment, which is expensive. Her grandchild often needs new clothes and shoes because of wearing them out due to the way he walks. This grandmother also feels that by looking after a disabled child she is doing a good deed and is entitled to charity.

Carers see that their children have improved, but some still focus more on the impairment than the abilities. This prevents them from planning for the future since their focus is still on physical improvement and 'cure'.

Education is also seen as very important. The grandmother wants her grandchild to go on to secondary school. Children took time to get adjusted to school. One of them was teased quite a lot, and in this case it seems that her epilepsy has been influencing her school performance, which has not yet been acknowledged by anyone. The father of this child feels strongly that he did not get the right to choose the education he wanted for his child. He still thinks that she would have received a better quality education at a special school for the physically impaired, but they refused to admit her.

Results of interviews with the children, group 3

These are the two children from group 3 who were interviewed by themselves without their carers. They have cerebral palsy but are able to walk. One has hemiplegia and epilepsy and the other is diplegic. The diplegic boy uses crutches and the girl walks with a limp. Demographic information is provided in Table 4.4. Both teenagers said they became disabled due to having convulsions when they were young.

Table 4.4. Demographic information, children in group 3

	Participant child	Age	Sex	Impairment	Ability	Onset of impairment	Social situation
Child 4	Child himself	13 years	M	CP diplegia	Able to walk with crutches, able to talk. Going to school, standard 4	At age of 9 months started to have bad fits after which he stopped talking and standing	Lives with his grandmother. They have a nice house. Grandmother does not say how she obtains her income
Child 5	Child herself	15 years	F	CP hemiplegia + learning disability + epilepsy	Able to walk, able to talk. Going to school, standard 6	At age of 4 she got cerebral malaria and was unconscious for some days. After this she became disabled	Lives with parents. Mother owns a shop. Father farms and does some business and is the main carer. She is one of several children

CP = cerebral palsy.

4.4.8 Physical well-being

4.4.8.1 Exercises

Exercises have given improvement in the past. Both of the children were not able to walk when they were little. Through the exercises they are now able to walk up to a certain point.

"I use crutches to be able to walk. When I reach home, I leave them and walk without them. I only use them at school. I can not walk far, I get tired." Child 4

The children realise that the exercises are no longer bringing about much change and they are no longer the priority in their life. They have realised that exercises have given improvement but are not going to give a cure, although they still hope for this. The girl thinks that maybe if she got better splints then her arm and leg would work and especially look normal.

"I no longer go for the exercises. I normally walk around for exercising and some days I walk from here [school] up to home." Child 4

"In the past, I could not even step down with this leg. I used to go for exercises [at CCBRT] so I have seen an improvement. I met one person wearing a splint on the leg - I heard at Msasani that if you wear that thing there is normally an improvement that occurs. I think it will also help me." Child 5

4.4.8.2 Health

The girl acknowledges that the epilepsy medication has improved her health. She had many fits when she was younger. Although she avoids talking about it directly, she mentions that she uses medication and has improved a lot.

"I am still getting epileptic medication ... I get improvement. Like the way I used to convulse in the past and it would come with a lot of force, especially in the hand and leg." Child 5

4.4.9 Emotional well-being

4.4.9.1 It hurts to be disabled

To look different and to be slow influences the emotional well-being of the teenagers. They see themselves as normal but have to deal with the fact that other people single them out as being different and need to get used to them.

"I see myself as just a normal child. It is difficult both getting tired and people looking at me differently." Child 4

If you are not able to walk fast or far it also means that friends need to adapt to this - and although they are willing, they sometimes forget.

"If my friends are going far and they are walking fast I tell them to wait for me. They say don't run away from X. I tell them not to walk too fast." Child 4

The teenagers realise that people pity them, and their friends sometimes laugh at them or treat them badly. This is difficult to deal with at an age when you are looking to form your own identity. They are looking for positive self-images.

"Because when I go there, they normally pity me and I feel bad as to why I am like that while all my friends are all well. But, what can you do and yet God has given it to you? You just leave it to Him. He is the one who knows everything even if friends laugh at you or tell you bad words, you just leave everything to God. Do not join someone in laughing at someone because it is only God who knows..." Child 5

The girl continues to dream of a cure. She keeps listening to different things that people tell her about miracle treatments that will cure her impairment.

"For example, I hear there is an American, I do not know if he is still around. I hear there is some medicine, he just gives you one tablet - like there is man who could not

walk but right now he is healed and the leg is straight. I do not know what medicine it is." Child 5

4.4.9.2 Empowerment

The girl enjoys helping other PWDs and uses this as a coping strategy. Her own improvement makes her want to advise others about what help is available. She gets hurt when she sees others suffering, and gets satisfaction if she is able to help them.

"I feel bad when I see others suffering while I am well. I like to advise and to encourage them ... I am one person that when I see someone suffering I am really hurt. For instance, I normally go to help that lady with washing clothes, I help her with some work then I go back home. I even wash her dishes." Child 5

They have become confident that they can be 'somebody' in the future. Both teenagers interviewed think they will work and earn their own living. They are aware of their different academic abilities. The girl would like to start working in a caring profession and the boy wants to go to secondary school and do something with computers. They feel quite confident that they will get assistance to achieve this.

"After school I will be someone who sits at the computer." Child 4

"I want to do nursing. To serve the sick and advise them and tell them in detail that there is a hospital that is doing so well." Child 5

4.4.10 Spiritual well-being

4.4.10.1 Hope and support through belief in God

Both teenagers get hope and support through their belief in God, and the girl believes that God helps in her healing. They also find it important to be a member of a church community.

"I say God is not bad. He made me this way but there is a day I will get healed and when I am alone I normally cry and ask God why I am like this while others are OK. What can I do ... I leave it to God." Child 5

Spirituality gives strength, and they believe that God can heal them.

"I go to the church for the saved people. There are lessons at the church; I normally go every evening. I love God so much. For example, when I am sick I get well; I could not work but now I can; I could not hold something, but now I can. This is because God helped." Child 5

The boy is sad that a local church he was able to reach is no longer there. He is no longer able to go to church. He enjoyed participating in church services although he was from a different denomination. They still come to visit him.

"I used to go to church, but nowadays the church has been moved so I no longer go. I just stay at home. They have built a house at the place where the church was and the church is very far. It is too far for me to reach. They come to my home to pray for me." Child 4

4.4.11 Personal development and material well-being

4.4.11.1 Increased activity level - independence

Both teenagers help at home - the boy to a lesser extent than the girl, which is also culturally influenced.

"I help my grandmother with small tasks. Like being sent to the shop for tea leaves. Things that are not heavy. I wash my clothes as the hands have no problem." Child 4

The girl, however, is almost doing more than other teenagers of her age. She will volunteer to do things. This does not seem to be acknowledged very much at home.

"I have managed to wash clothes, wash dishes and fetch water. I am doing so many things until people get surprised. I wash and I even bath myself." Child 5

4.4.11.2 Material well-being

The boy has crutches, which are far too short. This will damage his health and future mobility. They had the crutches made themselves and did not receive any support from CCBRT, although they went for exercises for a long time.

"The crutches right now they are small. They are too short for me. There is an old man who made them. He sold them to us. He made and brought them to me. It is my grandmother who gave out money for the crutches." Child 4

His grandmother is the one who looks after him. His mother lives somewhere else and although she works she is not able to support him. Items such as a school uniform and shoes are important for him to look like other children. They wear out quicker because of using crutches and dragging his feet over the floor, but his grandmother and mother are not able to buy him more clothes.

"Sometimes my grandmother goes to sell bags of water. My mother is the one who does some work at a hotel and right now she is at M. I need crutches, shoes and a new uniform. My mother she struggles to look for money to buy me a uniform but she is unable to." Child 4

4.4.12 Social well-being

4.4.12.1 Friends

Both teenagers have friends and go around with them, but the girl seems to be teased more. The friends of the boy will look out for him and help him. When they started school the other children had to get used to them, but now it is no longer a problem. They are accepted in their local community where people know them and are used to them.

"My friends know I am not walking properly, so even if I fall down they assist me to pick up the crutches. They no longer get surprised as they are now used to me." Child 4

4.4.13 Right to education

4.4.13.1 Education

Both children are attending a regular primary school. They both had to repeat some years according to their carers, but they do not mention it themselves. The boy is confident that he will pass and continue on to secondary school. The girl is aware that academically she is less strong and that she forgets things sometimes. She does not really understand why she changes so much from day to day. However, she has improved over the years. She does not seem to realise that this is a common feature with epilepsy, and that some days she might have small fits.

"I am now in Standard 4. I will go to secondary school and I expect that I will pass." Child 4

"I am now in Standard 7 [father says she is in Standard 6]. I am not doing so well nor so bad. I am average. The brain sometimes forgets what has gone in the head. I am really forgetful. So much... For example, if the teacher comes to class I sometimes forget what he is teaching. The brain, they say one side of the brain is okay while the other side is not okay." Child 5

At school they are treated the same as the other children. The children seem to feel there is no need to treat them differently.

"The teachers just see us equal but sometimes I fail exams just like other children. They beat you if you have done something wrong. Even me." Child 4

4.4.14 Summary, group 3 children

The two children have both improved in their walking and have seen the benefit of the physical exercises. However, exercises are no longer a priority. The girl still hopes for a cure. The boy mentions that his crutches are far too short but that his grandmother has not yet found the money to buy new ones. This means he is developing contractures due to the bad posture.

The children like to be seen as regular young people, but keep being reminded by those around them that they are different. This hurts and it makes it difficult for the teenagers to develop a positive self-image. The girl likes helping others, and helping other children with disabilities seems to be a way for her to relieve her own pain.

They get hope and support through their belief and are active church members. The boy used to go to the Pentecostal service as it was close by, but the church has moved and he is no longer able to go.

They both have confidence in their future. The boy wants to do something with computers. They go to a regular school. Both took time to adjust and had to repeat classes, but they say the teachers treat them equally to the other children.

University of Cape Town

4.5 Group 4: Children with cerebral palsy who are physically impaired and not able to walk

This group of children has cerebral palsy, which resulted in them not being able to walk. There is a very varied level of ability, from children who are almost walking to children who are not yet able to sit. This group was added because the group of multiple impaired was very large, and it was felt by the programme staff that the children who had a severe physical impairment only were different from the children who also had an intellectual disability. However, listening to the carers, even some of the children in this group probably have some degree of intellectual disability and definitely a learning disability, and some probably fit better into the severely multiple disabled group (group 1).

Seven carers were interviewed. Demographic information is provided in Table 4.5. Most of these children have had an impairment since birth or from the first few months after birth. The carers are not always fully clear about it.

"She was just born normally but she delayed to cry. I started noticing a difference when she reached 3 months old. I could make her sit but then she was unable and her neck also delayed to be stable. I went on but the neck was not becoming stable. When she was 4 months old, I had to go back to Muhimbili [hospital] because that is where I delivered. After explaining to them, they told me it is because she got some difficulties after birth. So they told me to go back and stay with her that way and that I would come after some time. I went home and after reaching 9 months, I went back. They told me they would write a paper for me to start attending exercises." Parent of child 5

Table 4.5. Demographic information, group 4

	Participant carer	Age	Sex	Impairment	Ability	Onset of impairment	Social situation
Child 1	Mother	10 years	M	CP diplegia	Able to walk a little with walking frame inside. Speaks a little – articulation problems. Goes to school, standard 1 – difficulties with academic work, has a helper	Child was born with vacuum extraction. After this, he was fine. Then he got severe malaria after which he started convulsing and developing problems	Stays with parents, he is an only child. Parents care a lot for him, mother started a nursery so he could go to school and be with other children
Child 2	Mother	5.6 years	F	CP quadriplegia	Only able to sit, unable to use her hands much. Unable to talk but does understand. Not started any education	Had yellow fever at birth. Started noticing at 4 months child was not right. At 6 months went to see a doctor	Lives with parents. Father is a policeman
Child 3	Mother	11 years	F	CP and hydrocephaly	Able to sit and crawl. Able to talk well. Goes to school, standard 1 – difficulties with academic work, has a helper	At 3 months started crying, was later diagnosed as hydrocephalic. Made to wait for 2 years; could not afford the shunt	Lives with parents, is the sixth born of a total of nine children
Child 4	Mother	9 years	M	CP diplegia	Able to sit and stand when holding on. Goes to school, standard 1. Able to talk well, has a helper	Delayed labour, with delayed crying, after this the child had difficulty breast-feeding	Lives with parents, both work at the airport food services. He is an only child
Child 5	Mother	7 years	F	CP quadriplegia	unable to sit – unable to hold anything – unable to talk – using signs for communication with her eyes – not started education – needs to be fed soft foods	Delayed crying, mother noticed after 3 months that the child was not developing well	Parents separated but father still provides for the child. Mother has now remarried and new husband accepts the child. Mother has one other child
Child 6	Mother	5 years	M	CP quadriplegia athetoid	Unable to sit, unable to do things with his hands. Able to talk	He was born well. Then he used to cry often. At 6 months realised he was delayed in development and this is when he started having fits	Lives with parents. He has one older sibling. Father works, mother is housewife
Child 7	Mother	8 years	F	CP hemiplegia	Unable to walk, able to talk. Weakness in one hand. Trying to enrol for standard 1	3 days after birth got ill	Lives with parents and has a brother. Mother does business

CP = cerebral palsy.

4.5.1 Physical well-being

4.5.1.1 Belief in the exercises

Carers see the physical exercises as the main treatment for their child. There has been a varied level of improvement. Carers have all seen their children change - although in the more severely disabled children the change was only small.

"I thank God because since I started these exercises my child is doing well." Parent of child 6

"Her neck used to fall from one side to the other, but as a result of the exercises she can now turn the neck to the direction she wants properly. ... she can also sit like the way you found her seated down. At first she used just to sleep but the exercises have really helped her and I am grateful for that." Parent of child 2

"He is doing well and I am so grateful as the exercises are helping him. I still take him to the church for exercises and they give us instructions on what exercises to do with him, so we do them at home and when he improves, we go for the next exercise." Parent of child 4

The carers still hope for further improvement.

"So I went on with exercise and I was told to find a tool for him to walk, so I had to look for a toy car. We used to put him there and walk around but he still has not made it." Parent of child 4

Carers attend more than one organisation for physical exercises. They think that the exercises will enable their child to walk, and believe that the more they go for exercises the more the child will improve. It also sounds as if they are trying to see whether the method of one service will work better than that of another service.

"So I used to go to Muhimbili on Tuesdays and Thursdays while at CCBRT I used to go on Wednesdays and Fridays. I just want more exercises so that she can be able to stand, and also toys so that the hands can become more active." Parent of child 2

"They told me that she should be going for exercises at Madafu in Ukonga, then after every month I take her to CCBRT." Parent of child 7

One mother moved for a while to a different town to get what she perceived to be the best exercises for her child. The mother could not stay so long away from home, which meant that the child ended up staying with relatives.

"When he comes to Dar he would continue with the exercises at Muhimbili and when he is in Moshi he could go at YWCA. After some time we now came to hear about CCBRT but I can't remember the age he was when we first went there. ... We continued going to CCBRT until the women who offer services to us advised us to go to the nearby centre [also run by CCBRT but carer seems to differentiate it]." Parent of child 1

One carer only realised after many years that there was a service for children like hers. This did not mean that they did nothing in the meantime - they found their own way of doing exercises with their child to increase the child's function.

"We used to teach her how to sit by supporting her back. So she could sit, and when the backbone gets tired she could bend forward so we could know that she is now tired and remove her. ... It took a very long time before she was able to sit because when she was 3 years old she could not sit. So the 4th year is when she managed to sit ... By the time we started coming to CCBRT she was 8 years and she was moving by her buttocks." Parent of child 3

4.5.1.2 No longer going for exercises

Two carers have stopped going for exercises. Carers with more severely disabled children have seen less improvement. Although they want to keep hope alive that exercises will work, they are not always able to keep going for the exercises due to other obligations. However, they do try to do the physical exercises themselves.

"For the time being because I have no one to assist me I cannot go to the clinic. I have two children, even just at home here when we are seated I give her exercises twice per day, in the morning and in the evenings. And anytime I feel I have no work, I normally give her exercises to straighten her legs and the back and also the sitting exercise." Parent of child 5

Another child has become too heavy to carry. Carers ask whether the CRW could come more often to the home again, since this service has been reduced:

"So my problem right now is that I am unable to carry that child to take her to the exercises because she is big. That lady from CCBRT is the one who sometimes comes home to give her exercises. She used to come twice or once per month but nowadays because X is at school they just decide any day and they pass by to give her exercises." Parent of child 3

4.5.1.3 Communication

Two children have communication problems. They are able to understand but are not able or only slightly able to pronounce words. Mothers have found their own ways to communicate with the child.

"She cannot talk but she uses signs. She shows signs by her eyes and I have learned to understand her very fast. She can't speak at all. She cannot pronounce a single word. If you tell her to say mama she just says aa aa." Parent of child 5

"She produces some sound but then you cannot tell what she is saying, but then you have to be so keen to understand what she wants. ... I mean she can recognise the names of her friends without any problem but now pronouncing them is her problem. She can now greet in her own way and it is something that she could not do at first. The exercises have really helped her." Parent of child 2

4.5.1.4 Equipment not sufficient or not appropriate

Although four of the children received a wheelchair, it did not always solve the transport and seating problems. None of the children pushes the wheelchair themselves. They are all pushed. The type of wheelchairs used all have the little wheels in the front, which are difficult to push in sandy soil. For one the wheelchair has become too small, and another does not use it at all.

"He has a wheelchair which we took from YWCA Moshi but it has become small. It just helps in taking him to school that's all. It has become small and it is hard to push it because around here the place has sandy soil." Parent of child 1

"I think right now we are pushing them because they are small. So I am wondering whether we shall be able to push them or not when they grow bigger. It is about means of transport for going to school. She is heavy; pushing her up the slope is not easy." Parent of child 3

"We were given a wheelchair from CCBRT, but with our roads here you must be very brave ... So we saw it was risky and therefore decided that he should just be carried to school and brought back." Parent of child 4

One mother feels it is not appropriate to sit the whole day in class in a wheelchair and asks whether a table and chair could be made for her daughter to sit on.

"I think she should be made a chair and table for using at school for writing because while seated on her wheelchair, she is forced to put the book on her lap so as to write because she cannot sit on a normal chair as she has no balance." Parent of child 7

Another mother had hoped that the child would be more mobile with the walking frame, but in the local environment the child is not able to use it outside. He only uses it inside for exercising.

"We were given this walking frame but it is useless because of the sand. [She points at the walking frame] This one cannot assist to take him to school. It cannot be used around here because of the sand so he just uses it in the house." Parent of child 1

4.5.1.5 Difficulties in getting equipment

Carers are disappointed to find that there are difficulties in obtaining proper fitting equipment. One child received a chair, which he used to fall out of. The mother found that he sits better in a washbasin. Up until now, they have not found a better solution, and apparently the programme stopped making equipment. The mother says that a local carpenter could make the equipment, but she does not know the design.

"He hasn't got a chair that he can remain calm in. No, someone must be beside him because he has a lot of energy and he can fall with that chair. ... There is a time they had stopped making equipment so they were few. Right now, I don't know if they have started making again. We did not get any equipment because many of us wanted and they had stopped making them. Parent of child 6

"I got the walking frame at the RC church ... I did not get any equipment from CCBRT."
Parent of child 1

Other carers have started to design their own equipment. They now feel empowered to try out their own designs.

"Before she was able to walk, she was ... First I was told to make some sort of car thing for pushing which is metallic, but I decided to make a local one from a piece of wood. I went to a carpenter so she can use it and she pushes herself to go and play with the friends." Parent of child 3

However, another carer found they were not able to make it of a good quality, due to their economic status. Carers feel that the programme should help more with equipment to improve their children's functioning.

"I can say that we are grateful for your help but such children need great help and not only from us parents ... I first made one [parallel bar] out of wood as that is what I could afford but, it has rotten because of rains and it is now broken. They then advised me to make a metal one, and you know the economic status of Tanzania. ... The more the things continue waiting the more the child lags behind in whatever he is supposed to do. So my advice is - I urge you as his doctors, you could be helping them with such tools so as to help us in life." Parent of child 4

4.5.2 Emotional well-being

4.5.2.1 Children feel hurt about being disabled

It hurts when you feel like a regular child, but realise that you do not have the same abilities as other children and are therefore left behind. However, friends and neighbouring children try to include them in their play and look for ways to make it hurt less.

"I think she sees that she has something less in her. As she can be playing here with her friends so when they leave they all leave at the same time and as you know she has no ability to stand and follow them. So she remains alone, so sad, and she starts crying. So, sometimes when they are leaving, they cheat her by pretending that they are coming back, and if they tell her in a polite way, she will remain there alone without crying and when they come back she gets excited again." Parent of child 2

"When others are walking she comes and tells me 'I want to also walk like my friends', then I tell her, don't worry you will just walk." Parent of child 7

One carer explains that her child feels hurt because others cannot understand her.

"She likes so much to be with her friends and you can hear her calling them to come and play, but then they do not understand her." Parent of child 5

4.5.2.2 Hope for a better future

Carers have gained hope for the future. They think their child will be able to walk and go to school. They have seen their children improve and have seen a difference in their functioning, which has given them confidence.

"My aim is that he goes to school and God helps him to walk. I believe he will walk. He will work on his aim until he accomplishes it ... I believe the more he grows ... but now he delays because his age mates are in standard 4." Parent of child 1

"From the way I struggle so much with the exercises, I believe that she will walk. After walking I think she will then go to school as she has brains." Parent of child 2

"Even though he will be unable to do some things here and there, he will have brains. From the way I live with him I have not said that this child will... or say that that's the end of him. No. I think God will help him in future so as to improve more." Parent of child 6

Two carers of more severely disabled children are worried about the future, that their children will not become independent enough to be able to go to school. One mother thinks that although her child has improved a lot, she will remain dependent on them because she is disabled.

"For sure I don't understand what she will be able to do in the future. I struggle and do everything I can to her but I don't know what God will enable her to be. Because she does not know how to write ... She can write numbers 1-10. She can also write 'ba be bi bo bu' but then she gets problems in joining them." Parent of child 3

"According to me, I see her as being disabled and so she is of no help. She will still need our help even at the age of 20 or 30 years." Parent of child 7

4.5.2.3 Increased self-esteem of the children

The children have gained in confidence; one wants to become a doctor and another a broadcaster. The one who wants to be a broadcaster still does not speak very well but seems to admire that job. Others really want to learn to walk and see this as the way to go to school.

"He says I will read so much to become a doctor. So I ask him will you make it to be a doctor? He says 'if I work hard I will be one'." Parent of child 4

"For him he really desires to walk. He says he will one day walk and he even says when I start walking I will go to school." Parent of child 6

4.5.3 Spiritual well-being

4.5.3.1 Hope and support through religion

When your child does not improve much, it seems to help to put your trust in God.

"I think I should just pray to God. God will enable her. The way I see her struggling, it is just the fevers that take her back again. If it were not the fevers she gets every now

and then, she could be very far." ... "Nowadays she just gets the normal fever as other children. Her father just says that God will help her." Parent of child 2

4.5.3.2 Participating in religious activities

Carers find it important that the children take part in religious activities. Some carers will carry children who are not mobile enough to the religious services. Children themselves find religion important and enjoy going.

"He likes praying so much. Even if you place food on the table, the rest of you can begin eating without praying but X can't eat without praying. ... I normally go with him to the mass I attend as there is no child that can carry him to church. We even go with him to home churches just as usual. He likes it and he believes." Parent of child 4

"She really enjoys going to the Madras and she even reads if the teacher writes something on the blackboard until the teacher gets surprised. ... I have never taken her to the mosque." Parent of child 3

One child goes to a different church to that of her family since it is closer. The family is Lutheran but the child goes to the Pentecostal church.

"The church he goes to is not the same church we go to. We go to Lutheran but he goes to Assemblies of God. We take him there because it is near. God is one, provided you just pray." Parent of child 1

One more severely disabled child is not taken since she is not able to sit by herself. The carers are afraid the child would feel discriminated against because she would be lying down when everybody else is sitting.

"She cannot go to the mosque, because she cannot do anything. It would be at least better if she could be able to sit. So if you go with her you will be forced to lie her down while people are seated and there she will feel discriminated against because she will wonder why everyone else is seated while she lying down on the floor. And if you tell her X, today is Friday I am going to the mosque for prayers, she tells you that it is okay." Parent of child 5

4.5.4 Personal development

This is a very diverse group, from children with greatly improved independence to children who are still dependent for most things.

4.5.4.1 Children being dependent on mother

Three of the children are still very dependent on their mother. Although they made some improvement and are able to play a little, they need help for everything.

"Now the neck is stable and she can also sit like the way you found her seated down. At first she used just to sleep but the exercises have really helped her and I am grateful for that." Parent of child 2

"She cannot do anything; I do everything for her (washing, dressing)." Parent of child 5

The mothers especially need to make sure that their children are eating well since they deteriorate quickly if they do not get proper nourishment. The mothers also need to make them special food.

"You know such children need to be with their mothers most of the time so that they can feed them when they are hungry, because considering their condition and if they don't also eat well it becomes bad." Parent of child 6

"She has not really managed to eat because her jaws are not strong, but then she tries. If you prepare her the soft foods she can eat but not roasted bananas and meat. But if the meat has been grinded she can eat." Parent of child 5

One child tries to find her own way of doing things, i.e. through using her legs. The mother is under the impression that this is not good, since she feels that the child should learn to do it using her arms.

"So most of the time, I sit with her and prevent her from using her legs instead to use the hands. If you put her panti there, she pulls it using the legs, then I tell her to use the hand. You find that she knows everything but the way to use it is the problem." Parent of child 2

One child has learned to indicate that she needs the toilet, and she no longer dirties herself. This has reduced the amount of washing for the mother.

"There are quite a number of things that she can do right now; for instance, if she wants to help herself she tells me as she does not help herself in the clothes unless I am not around and the person with her can't understand her. But if I am with her she shows me she wants to go for a short call or a long call or maybe if she is feeling hungry she just does with the eyes. That is the benefit I have got from attending the exercises." Parent of child 5

4.5.4.2 Children who have increased independence

Four other children in this group have increased their independence, although the focus of the carers remains on teaching their children to walk.

"We have taught her how to wash her light clothes and she can also wash plates and cups. She was unable to crawl because of the weight of the head, but as a result of exercises from CCBRT she can now crawl. We are also teaching her how to use crutches because if someone supports her from the back she can walk with them, but she cannot do it alone because her knees are not strong enough to support her." Parent of child 3

Toileting remains an issue. The children do not seem to have a proper place to go, which is embarrassing. Due to their mobility problems they are not using the pit latrines. Carers have not been able to find a solution so far. This is a very embarrassing situation for the children.

"She can even go to help herself whenever she feels like because we have bought her a potty to avoid her using the toilet we use because we share it with many other people. ... She feels bad about not doing it on the toilet but there is no other way out."

Therefore, whenever she wants to help herself she must call someone and she never helps herself at the neighbours." Parent of child 3

Children want to be independent and want to participate like anybody else. This is why the children have learned things, but the carers do not seem to understand the importance of practising. Some carers are overprotective, and others think their child's physical impairment should improve first, and therefore do not expect their child to participate.

"He really likes to participate. Even when you are seated here with someone else and you send the person to bring you something, he usually wants to go even with his condition. Even if the item is for holding in the hands he will hold it and then look for a way of walking on his knees and bring you the item. He is a child that really likes learning." Parent of child 4

"She can wash and even take tea and eat by herself. Because one of her hands does not function, she tries to dress up by herself but then she cannot. If you are washing utensils, she moves closer and washes, even if you are washing clothes she comes to help." Parent of child 3

One mother asked for practical advice about how her son could become more independent. She is afraid that if he remains dependent on others for everything it might hamper him from going to school in future.

"He needs to be able to sit by himself. He must be someone that if he wants something, he can be given it and puts it in the mouth by himself. ... For example, if you take him to school he should be able to take his water and drink or even juice." Parent of child 6

4.5.4.3 Mothers adjusting their lives

Mothers adjusted their lives to accommodate the needs of the child. One mother stopped working and started a nursery school so it would offer an opportunity for her child (who is an only child) to be with other children. She decided to start a class herself rather than sending him to a local nursery school. Her son has now started primary school with these children and her mother is looking at how to expand the school when her son improves further.

"I was employed but I had to stop working because of my child's condition. I decided to start a nursery school here so that children could come and play with him. ... I have taught them and they have all gone to standard one together with my son. I am planning that after he improves well, I will look for a bigger space and open up a bigger nursery school." Parent of child 1

Carers of the more severely disabled children feel that they cannot leave their child with anyone - it would be too much of a burden for the other person. They also believe

that others might not look after the child well due to beliefs they have about the cause of the disability. Therefore, one mother always takes her child with her.

"If I am leaving I leave with my child. I go with my child to everywhere I go. Come what may, I must go with him. I cannot leave him with someone else because the person will think that you are making her to sit in one place. ... if you leave the child with such a person, you will find that she is not happy in her heart. She will take the child but with a bad heart so when I leave here, I am forced to go with my child." Parent of child 6

One mother solved her mobility problem by carrying out a business from home so that she can combine looking after her child with making a living.

"I am a business woman and I do my business just here from home." Parent of child 7

4.5.5 Social well-being

4.5.5.1 Having friends

Children find ways to make friends, even when they are not very mobile. Some children are very popular and are known by many people in the neighbourhood. Other children insist on sitting outside, which gives them the opportunity to meet other children and to follow what is going on.

"He has so many friends, old and young. They really like him. I do not know what to say about X but he has the luck of being liked by people. When I pass in the neighbourhood there are so many people I don't know but hear them greeting me 'mama X how are you, mama X how are you?'. He is so popular. If you tell someone to take you to mama X you will even be brought by a very small child." Parent of child 4

"He doesn't like sitting inside the house. Most of the time, when he wakes up, the first thing he wants to do is to get out. He just sits and plays with others. His friends come around his basin and they play from there as he watches." Parent of child 6

Playing also helps to improve function. Children will try hard to improve; they try to move and to get up to see what is going on. They are also stimulated intellectually.

"Her friends are even the ones that contributed to her being able to sit now as they used to play near her and you would see her struggling to sit up. She just used to sleep but now if you make her go to sleep she does not want to, and that is how she was able to sit." Parent of child 2

One mother does not like her son to go off the compound as he gets chest problems easily. He now depends on friends coming to him.

"He depends on children coming here. Outside there if he breathes dust he gets chest problems. I don't know but I think it is because he does not do enough exercises to allow enough air in the lungs. ... If it is his birthday he invites his friends and he is known all over this area. They like him and most of the time he sits on the veranda so children come there to play with him." Parent of child 1

4.5.5.2 Effect on siblings

Siblings are very caring towards their disabled brothers or sisters; they will go out of their way to help them. They assist them with schoolwork, help in taking them to school and try to include the child in their activities and stimulate them in their development.

"She has three followers. One of them is in class 3 who helps her do her class work after she comes back from school. The younger one teaches her how to read and write. There are 9 in total and they take good care of her. Even if I am not at home, they do not go to play very far. They play near her or if at all they have to go away, they go with her as she crawls." Parent of child 3

Siblings help the carer to care for the child, and some have developed a communication system so that they can help to explain what the child wants.

"There is a possibility of leaving her because she has a sister who I can leave her with." Parent of child 2

"But I have a niece who is around 4 years old, she is used to her. She understands her very well. She gets most of the words and she can even say 'mama Asha, Asha wants to help herself'. She really understands her." Parent of child 4

4.5.5.3 Effect on partnership

The participants in this group, all of whom were mothers, felt that although fathers are interested and care about their children, the main responsibility for the child's care falls on the mothers. Fathers are the ones who remain working and earn the family income. They therefore have little free time, but when they can they will share responsibilities and help with the physical and communication exercises.

"My husband is a policeman; he is normally at work all day. He assists me though he has not time to take her. The day he is around I show him what to do and he does the exercise to the child and he even teaches her how to talk." Parent of child 2

"My husband has no problem. We struggle together. Even today I have left X at school and he is the one who will go to take her from school. He likes her so much and I am grateful." Parent of child 3

One mother was left by her husband, but the husband still provides for his child and comes to visit her and does things with his child. The mother is now remarried to a man who accepts the child and loves her as his own.

"I don't really understand why he left me because we used to live ... He told me he would be providing everything for her and it is true, he provides for his child. ... When he comes, he takes her, goes to walk with her and then brings her back later. Right now I have another husband who helps me. I told him that I have such a child since we started our friendship and when he saw her, he accepted her, and we decided to marry and up to this day he loves her like his own child." Parent of child 5

4.5.5.4 Not having another child

One mother does not have another child because she is worried he/she might be disabled. Another mother is worried that she will not be able to give the disabled child enough care if there is another child.

"Right now I can say that it is only X. I got another boy child in May 2003 through an operation but by bad luck he died in August 2003. Since then I have not thought about it again. I have become worried to some extent but I say anyway let me just continue taking care of X as I feel having another child will bring more burden. I don't know why it happened so." Parent of child 5

"I will not have another child at the moment because this one has to be carried like a child so having another child will be difficult for me. I am waiting until he grows a bit bigger." Parent of child 2

4.5.5.5 Effect on the family

Having a child with a disability is a shock and brings pain, but it also enriches your life.

"We can say that there is a change in the family because before something hits you, you don't know its hardships or how to go about it or how to receive it. ... There are also places I didn't know of and maybe I would not have known them for life. Places like CCBRT I don't know what would have made me go there, but I have come to it because of the child. I have even known people I could not have known in my life." Parent of child 3

Carers find it important that the child feels like a normal member of the family. They try to ensure that the child is able to take part in all social activities so that he or she does not feel discriminated against or segregated.

"The way we have stayed with him, we are not used to discriminating or separating him. We really love him. We involve him in so many things. If there is a party he attends, he attends his friends' birthdays, he attends weddings and send offs.... When the cousins come they even take him to Mbeya for 2 days and he comes back. So he is free." Parent of child 4

"We also travel everywhere with him. He does not miss going to church every Sunday. When going to visit friends or relatives we must go with him. We carry him when we go to the village like maybe for a holiday. We just carry him." Parent of child 1

4.5.6 Right to education

4.5.6.1 Type of school

The carers advised that CCBRT should encourage children to start at kindergarten like all children, instead of starting straight at primary school. Children need time to adjust to school - even more so when they have an impairment.

"She was in standard 1 last year but we decided to make her repeat the same class because of her problems, and she is now coming up well. It was difficult for her the first year because first of all she was not used to being with others, and she could not also understand when in a group of people because she didn't go to nursery school. ... So

my request is that if there is that possibility then they should go to nursery first and then join the normal schools." Parent of child 3

Carers presumed their child needed a special school just because they had a physical impairment. After advice from CCBRT, one parent is now very happy with the improvement of her son at a regular school. The child has more self-esteem and now wants tuition so that he will be able to do well and go on to Standard 2.

"He went to a nursery school at YWCA for the intellectually disabled children. ... So keeping him there we came to discover that he was learning things he was not supposed to as he was imitating the foolish things which the other children who were intellectually disabled were doing ... So they told us to take him to a regular school ... So we transferred him. He is doing quite well and if you compare his past and present exercise books, they are quite different. ... And he says I must make it and go to standard 2. He is coming up in his way of thinking and even physically." Parent of child 4

One mother reported that her husband became very upset that his physically disabled daughter was put in a special class for children with intellectual disability. He felt she had the right to be in a regular class. Carers have to talk a lot at school to get their rights and to change the attitudes of the teachers. This father (of child 7) received some help from a neighbour teacher:

"When I (mother) went to enrol her for school she was accepted very well. When I then took her to school I don't know how they saw her but they put her in the same class with the intellectually disabled children. My husband was annoyed why they had put her in this class while she was not intellectually disabled. So I went to school to talk to the teachers about that but they refused and said she must stay in that class until they see her progress and behaviour is when she can be taken to another class. So I told them it is okay. My husband said that was impossible to put her in that class and he decided to call at school."

4.5.6.2 Wanting to go to school

Children want to go to school like other children. However, they do need some time to get used to the school, and for the school children to get used to them.

"She really likes going to school and if you tell her not to go she really cries and gets annoyed. She really likes school. She even wakes up at 6 am and tells me is it time so that I can wake to prepare. Parent of child 3

"It is last year [her first year in school] that she got problems because some were laughing at her because they used to find her looking strange, so they used to stare at her, but the teacher had to talk to the pupils not to isolate her and I am grateful that she is now well with the others." Parent of child 3

Another child is not going to school yet, and wants to go to school like other children.

"About school, she tells me every day to take her to school like M. M is the younger one. She says I want to go to school just like M. He is in nursery school." Parent of child 7

4.5.6.3 Advocacy

The programme encourages carers to send children to school and informs them of their rights. Some carers had not thought that general schools would accept their child. At some schools, CCBRT gives training sessions to the teachers and provides a helper to stay with the child. However, CCBRT does not seem to help all carers in the same way. Some carers have to do a lot themselves. Some manage, but the schools do not accept children unless carers demand their rights. They need to go several times before the child is accepted.

"At first they [the school] used to refuse but then after the father went there several times, he was accepted." Parent of Child 4

"If it were not for CCBRT we could not have taken him to school because there is no special class for such children in the school. I didn't try but we don't see such children in these schools, so the probability that they could refuse him is there. CCBRT took them to school with their helpers. ... The head teachers and the class teachers were called to attend a seminar and they were taught there. This is when they started accepting such children in schools. Otherwise, there is nothing like that in our government." Parent of child 1

4.5.6.4 Right of severely disabled children to education

Carers of the more severely disabled children want their children to go to school, but they are unsure if their children will be able to. Some have been refused, and carers are told their child has to be more mobile and be able to communicate.

"There is a plan for school and that is why they tell us to follow the exercises so strictly ... I was just praying God that she manages to talk; then from there we shall now start thinking about school." Parent of child 2

"If he would be sitting I could have asked for a chance at the neighbouring nursery and I would be taking him there. Even if he cannot write, he would expand his brains." Parent of child 6

"I don't really know if there are government schools. [At this special school] they told me they could not accept her. I don't know if there is another school ... There are others whom we are with together at the exercises, they have already taken their children to school because their conditions are a bit better as they can sit and so they have been accepted." Parent of child 5

4.5.6.5 Helpers and rehabilitation

Some of the children have been given a helper by CCBRT. One child seems to have a helper which helps more than is necessary, but the carer is happy about it.

"For instance, if this one here wants to go to the toilet he must be taken. Or if he wants drinking water the lady has to open his bag and give him water. Sometimes when writing, the lady has to support his hand where she thinks he cannot write. Or when the teacher is teaching and as you know the pupils are so many, so the teacher cannot

attend to all of them, so this helper has to be close to him to explain to him what the teacher is teaching. They are of great help. It is hard for us carers to go and spend the whole day at school with the child. Parent of child 1
Child 1: "I am not able to write, the helper writes for me."

One mother advocated for the rights of children whose carers are not able to get them to school every day. She reported that you will only get a helper when you have stayed with your child first yourself. She is advocating for more help for those carers who are not able to do this, in order for those children to also get an education.

"There are some carers who wish to send their child to school but they are not in a position because there are some who are dependent because they have no husbands. Such a person has to try out all means to get something to eat and so taking the child to school she feels that she is wasting time because this same child will want to eat after school. So it is my request if CCBRT could use all means they can to help such children to go to school to be educated." Parent of child 3

4.5.7 Summary, group 4

This is a diverse group of children, but the majority have seen benefit from the physical exercises to a greater or lesser degree, although the more severely disabled children have not improved much. Carers feel that the more exercise the child gets, the more the child will improve. Some still hope for a cure, despite the level of disability. Two of the carers no longer attend the exercises.

Carers complain about the difficulty of getting equipment, and that when they receive equipment it is not always appropriate, well fitting or suitable for the problem. In this group quite a few carers received a wheelchair, but some do not use it for different reasons. They all find the chair difficult to push through the sand.

Children like to be seen as like other children, and feel hurt when others differentiate them. The carers whose children have improved have increased confidence in the future; however, one carer whose child goes to school is worried that her child might remain dependent on her for the rest of her life. The children themselves have hope for their future, although some are worried that they will not be able to walk.

Carers get hope and support through the church. One child goes to a church of a different denomination because it is closer to the family home. The more severely disabled children do not participate in religious services.

Three children are still dependent on their mothers for most things, while four children have improved and are able to do more activities. However, due to the focus on their physical abilities and exercises, the carers do not expect their children to participate in self-care and household activities. It is more the children themselves who try and want

to participate. Carers do not seem to realise the benefit of participating in activities, even for the physical development of the child, although one parent did comment on the benefit that playing had had on her child's increased physical ability.

Mothers have reacted differently to having a disabled child. One mother stopped her work and started a kindergarten in order for her child to be with other children and to be able to go to school. Another mother manages to do business from home.

Children find that having friends is very important, and they like to be included in their play. Siblings are also seen as a great help and a support to both the child and the carer. Two of the mothers are worried about having another child after having a child with a disability.

Education is seen as very important. The carers recommend that the children first go to kindergarten like other children. Getting used to school takes some time. Carers are grateful for the support with getting their child into a regular school, but carers are extremely active themselves to get their child enrolled. The carers of the more severely disabled children are worried. They want their child to go to school but do not know if such schools exist. They see other children start school but realise that those children are physically better.

Carers are grateful for the helpers since they enable their child to be accepted at school. However, apart from taking the children to the toilet, their role is not very clear, particularly with respect to the rehabilitative approach. They appear to over-assist the children, which limits the children's development. For children with learning difficulties helpers could be extremely useful if they were an integrated part of the rehabilitation programme.

4.6 Conclusion

In the evaluation, four different groups of carers of children with disabilities were interviewed. The findings of each group have been presented. They showed that there were similarities between the groups - but also vast differences.

Carers described improvements in different quality of life areas, especially improved physical well-being and personal development. Children who functioned on a higher level had greater changes than the more severely disabled children, although carers would like to see further change in all of the groups.

It became clear that children and carers have changing needs over time. The carers perceived it as very important to improve the physical functioning of the children when the children are small. However, when the child grows, the needs change - especially if it becomes clear that there might not be a cure. Children and carers start to refocus and adjust their priorities. To do this they need emotional and spiritual support, and they expressed the need for advice with planning for the future.

The findings make it clear that children with cerebral palsy are not a homogenous group, and need to be treated according to their needs. This will be explored further in the following chapter. The findings will help the ART CBR programme staff to understand better how the participants experience the services offered by the programme, and what they would like to see improved.

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CHAPTER 5

Discussion and recommendations

5.1 Introduction

The WHO has recommended CBR as a strategy for improving quality of life (Helander, 1993). The aim of this evaluation was to determine how the activities of the ART CBR programme influenced the quality of life of children with cerebral palsy and their carers, and the perceptions of carers of the usefulness of the programme's activities.

The selected children with cerebral palsy were divided into four groups according to their functional and mental ability. The findings show that these groups have similarities but also distinct differences in quality of life. In this chapter the findings of the study are discussed and recommendations are made based on these.

5.2 Physical well-being

5.2.1 Need for physical development

Across all the groups the carers view the CBR programme as a programme that offers individual services mainly focused on physical exercises and medical care. Carers perceive rehabilitation as successful when a child is physically able to function well, in particular when the child is able to walk.

In the Tanzanian culture there is a generally negative role expectation for PWDs. They are viewed as dependent and not able, as people who will be a burden to the family (URT, 2004). Not being able to walk well is obvious and immediately labels a person as being disabled, which in general is seen as a barrier to having a good life. This could explain why mobility and normal limb function are viewed as so important by the carers.

Carers value physical exercises highly. The institutional culture of the programme supports this by putting great emphasis on physical exercises. Where physical improvement occurred in children, carers expressed their satisfaction, and this was seen to give hope. As the children grow older the realisation comes that there might not be a cure, and carers start to wonder how far their child will be able to improve. This is often the time when carers stop taking their children for exercises, as they no longer see much of a benefit, and with the child growing it becomes more difficult to carry them.

Although a large percentage of children with cerebral palsy will not be able to walk normally, many will be able to function independently, depending on the level of initial impairment. However, the severely disabled children will need attention throughout their lives. The CBR programme needs to adapt the type and intensity of the service to reflect the changing needs of not only the child but also the family (Geller & Warren, 2004).

5.2.2 Need for appropriate and affordable equipment

Another commonality among the groups was the difficulty of obtaining appropriate equipment and the expense thereof. Carers commented on their difficulties in obtaining equipment through the programme. A few carers had taken the initiative to make equipment themselves. They feel that they should get more support, both practically and financially.

Having a child with a disability is associated with significant financial outlay, and in general, the more severe the disability the greater the expenditure. This severely strains finances in the context of families with limited financial means.

5.3 Emotional well-being

5.3.1 Need for emotional support

A number of carers in the groups reported living with a high level of stress and emotional strain. Blame and guilt were common experiences for the mothers, particularly in the group with more severely disabled children, as their physical ability had improved minimally. Families are in need of hope and support. The programme addressed this to some degree by giving information to the carers about the causes of disability. Although this information is perceived as useful, it fails to relieve the enormous stresses faced by families.

An extreme example was provided in the study by one of the fathers being under so much stress that he had thought of suicide. To increase the coping abilities of carers the programme needs to offer more opportunities to grieve the experience of multiple losses, and to look for ways to build emotional resourcefulness (Lorenzo, 2003).

5.3.2 Need for empowerment and control

Carers of more severely disabled children have had to take on special roles. These include paying attention to health promoting behaviour such as nutrition, exercises and relaxation. There was a lack of confidence in carers about their mastery of these skills. They feel disempowered and are unsure of how to deal with their child's disability, and therefore the carers perceive themselves as having poor quality of life.

Support systems are important for carers with severely disabled children. The mothers of severely disabled children have a great need to share their experiences with mothers who are in a similar situation. At the clinics they meet mothers who have children who are very differently able, and everything revolves around exercises. Severely disabled children appear to be the most limited, and this causes significant distress for the mothers. The noisy, restless environments at the clinics are not conducive for sharing social and emotional problems and achievements.

5.3.3 Need for self-esteem

Parents need to have the confidence and self-esteem so that they are able to change their situation. One woman with a severely disabled child evidenced a change in self-confidence. She was encouraged by the individual interview with the researcher to start an income-generating activity, which has given her more self-esteem. She decided to train up a relative to look after her child, and no longer feels she is the one and only person able to look after her child.

Children themselves see themselves as ordinary children. However, they are continuously reminded of their otherness, especially when in new environments where people do not know them. The children are made to feel different, which is very painful. They have learned to deal with this with support from their families.

The older disabled children who were interviewed identified the importance of spiritual support and the sense of belonging they obtained through participation in religious activities.

It would be beneficial for the children if the programme could develop a support group in which children with similar disabilities get the opportunity to meet each other in a relaxed environment.

5.4 Need for spirituality and spiritual support

5.4.1 Getting support through religion

The importance of religious belief and practices was evident. Most of the interviewees were religious, belonging to either the Christian or Muslim faiths. Their religious belief provides the carers and the child with strength and hope. If their own religious institutions are not easily accessible for worship/prayer, children will attend a nearby church, even if it is of a different denomination from their carers.

Carers of severely disabled children were most vocal about the support and hope they received through attending evangelical prayer services. In this group all carers, regardless of religious faith, would attend these evangelical prayer services in order to pray for their children to be healed. This revealed the need of the carers for hope and support. It might be important for the programme to work together with the religious organisations since they address an essential need for their clients.

Apart from one child, the children with intellectual disabilities who were mobile did not participate in the religious activities due to factors such as incontinence and lack of social skills.

Carers interviewed also used spiritual language, especially when they spoke of situations where they felt they were not in control, and referred to 'God will know' or 'I am leaving it in the hands of God'. The ART CBR programme should investigate whether barriers that prevent some children from participating could be removed, and whether partnerships could be developed with the religious groupings within its catchment area.

5.5 Personal development – increased ability

When carers spoke about the development of their children, they focused predominantly on the improvement in their child's mobility and physical functioning. Carers can be so focused on the difference of their child and the search for a cure that they overlook the other abilities that their children have. Looking for a cure also prevents the parents from planning realistically for the future. The carers of severely disabled children felt too afraid to look too far ahead. They rather left it up to God.

When children become older and both children and carers start to realise that they will have to live with various levels of impairment, they start to refocus and adjust their priorities. The carers expressed the need for advice with planning for the future and

with issues of bringing up a child with a disability. Other carers whose children were more functional and who had refocused were more confident about their child's future opportunities.

Communication was seen as an important skill for the future development and opportunities of the child. It facilitates choice and participation for the children and reduces the child's isolation. Carers of children with communication difficulties felt insecure as to how they could improve their child's communication ability.

The carers mentioned that their children wanted to be like other children. Participating in daily life activities such as self-care and household activities is very important. For children who also have an intellectual disability, it is even more important to stimulate daily life activities since by participating they will learn a lot of cognitive, behavioural, social and communication skills. This was not realised by the carers, who seemed unclear as to what to do to with their children apart from physical exercises.

5.6 Social well-being

5.6.1 Need for belonging and integration

No matter how severe their impairment, children enjoy being in the company of other children. They like to participate and to feel included, and they enjoy playing with other children. Families will put a lot of effort into ensuring their child is able to play with other children. One carer commented on the fact that wanting to play and to be with other children motivated their child to try to become more functional.

However, in other families the children stay inside a lot. Sometimes, with the more severely disabled children, this is also due to environmental circumstances since there is little room outside and no shade. Play is the way in which children learn and develop. The programme could be more proactive in looking at how to adapt the environment. Often it would require just a small investment such as a shade cloth or a special chair to adapt the environment to create a place for the child to sit in the company of others and be able to participate in their play.

5.6.2 Need for a social network

Carers described how having a child with a disability changes the family interactions. Children tend to have close relationships with their siblings. However, the siblings of

the more dependent children sometimes have to assist more with care for the child than normally would be expected.

When there is a good relationship with some of the extended family, they can be of great support in enabling the mother to have some time for herself or to enable her to go out. The extended family will agree to have the child and even provide the intimate care needed by the child. In other families in which the support network has broken down, isolation is a significant risk.

The relationship of partners with each other varies, from mothers who have been left by their husbands due to having a disabled child, to other carers who have very supportive partners. Mothers are usually the main carers, but often when the fathers have time they will help with the care of the child. One father interviewed was actually the main carer as the mother worked full-time.

5.7 Need for education

Education gives a child access to more opportunities, and is perceived by the carers as a way to a better future and better quality of life. The ART programme has tried to address this by encouraging carers to enrol their child into primary school, and by giving education to some teachers about children with disabilities.

This service is offered to certain children, mainly those who are more mobile and functional. However, all carers interviewed with school-aged children find education important and want their children to receive some form of education. They are not sure about what is available and what their rights are. They perceive the main issue preventing their child from attending school to be the ability to transport their child to school every day, and their child's ability to sit and to communicate.

Although all carers with school-going children were happy their child was attending, they did not all feel free in their right to choose the type of education they wanted for their child, and did not think their children were getting the quality of education they deserved. It would be beneficial to arrange meetings with carers of school-aged children to discuss the different types of education and support available, and to facilitate that carers become active partners in fighting for the right to quality education of their children.

5.8 Implications for the CBR services

5.8.1 Need for integration of services

In the current structure, the CBR programme has developed the provision of physical exercises to a high level of excellence, but there is a lack of access to other services. The institutionalisation of the CBR programme leads to lack of flexibility and access. An integrated interdisciplinary approach is needed to rebuild confidence and well-being.

5.8.1.1 Integration of medical and rehabilitation services

This is especially seen around a syndrome such as epilepsy. Medication is prescribed at a different place from where it is obtained. Currently a district or national hospital provides the diagnosis and prescription. Some people then go to CCBRT hospital, which provides the medication at an affordable price. This is highly appreciated by many of the carers. However, epilepsy occurs with and causes a number of different impairments. In all the groups interviewed, there were children with epilepsy. Communication about how well a child was doing at home and at school does not seem to be an integrated component of medication provision, even though medication has a significant influence on the child's overall behaviour and ability to cope. Provision of medication should ideally be an integrated part of the rehabilitation process. This requires an improved communication system between the rehabilitators and the medical personnel. Integration of these services could greatly improve the quality of life of the children involved.

5.8.1.2 Integration of exercises into daily life activities

Exercises are seen as very separate from the general daily life activities of the child. Neuro-developmental methods focusing primarily on physical exercises have not yet been scientifically proven to have any positive effect on the child's motor development (Butler & Durrah, 2001). Currently a more family-centred functional approach has been promoted, whereby exercises are integrated into the daily life activities of the child. Findings indicate that the family-centred approach to therapy has the potential to facilitate change in the motor performance of children with cerebral palsy (Law *et al.*, 1998). Physical exercises should be integrated into the child's daily life activities at school or at home instead of doing separate exercises (Pollock & Steward, 1998).

This might be an important aspect for the programme to explore further all carers see exercises as something you do separately at allocated times. Apart from increasing and maintaining function, equipment should also improve functionality. Carers experienced difficulties in obtaining equipment. It might be beneficial if the programme reviews its seating assessment and equipment policy, with the objective of making equipment more accessible and appropriate. Equipment provided should fit properly (e.g. chairs, orthosis) and serve the need.

5.8.2 Overall development of the child

The focus of the carers has been on functional exercises. This worked well to some extent - but not all children were able to learn to walk, and even when they were able to walk they often still had difficulties with other activities. The needs of the children are varied and change over time. It is important that the programme addresses these varied and changing needs. Children and carers need to be shown ways in which the child can be more independent, and how the child can participate more in the home and community environment. They should understand that when a child is stimulated to participate in home and community activities it will also develop the child's physical and communication abilities. Acknowledgement of other abilities of the child by the carers and family will improve the self-esteem of the children.

For the group of severely disabled children who are unlikely to be able to walk or become very functional, the programme could look at it could reduce the burden of care. It could offer opportunities for development and growth not just of the person with the disability but also for the immediate carer.

5.8.3 Need for positive self-image

It is also important to look at ways to increase the level of participation of children in their treatment. The programme could also look at what more it could do to increase self-esteem, and for the children to develop a positive identity. Opportunities should be provided for children to express their feelings, to communicate and identify their strengths. Techniques such as music, art, role-play and story-telling can be used to restore self-worth and dignity and to improve self-esteem. It might also be useful for children and their carers to meet up with adults with disabilities who are earning a livelihood for motivation and hope.

5.8.4 Need for home visits

The carers comment on the reduced number of home visits by the CRWs and physiotherapists. It seems that it is mainly the mothers and grandmothers who take the children to the exercises. When children become older and heavier it becomes more difficult for the carers to carry them to the centres. They also comment that these clinics are not conducive for all children as they mainly focus on physical exercises. There is a need for home visits to continue and even increase when children are older. This will ensure that the more severely disabled children also continue with exercises, and the carers will feel more supported. It could also be a way for the programme to work with the immediate family and local environment.

5.8.5 Education as part of the rehabilitation process of the child

The educational programme seems to be separate from the exercises offered by the programme. The educational development of the child and the general functioning and participation at school does not seem to be an integrated part of the overall rehabilitation process. The carers and children would benefit from a more integrated approach whereby CRWs move from being used mainly for physical exercises to also being involved with the inclusion of the child at school and at other services and activities in the community.

The helpers at school can be a valuable resource, and they should be included as an integral part of the rehabilitation team so that they are able to follow the same aims and objectives as the other rehabilitation staff. A rehabilitation file that functions as a communication book could be a useful tool.

Another topic mentioned by the carers is that the helper is there to help with toileting. Toileting is an important issue for many of these children, even at home. For most people it is very embarrassing to need help with toileting, and most children who are able to attend school should be able to learn to toilet independently when using an adapted toilet facility. Accessible toilets will be of benefit to more children in future. The standard design of toilets in primary schools in Tanzania needs to be addressed and efforts need to be strengthened to promote a more inclusive design.

5.9 Need for family support services

5.9.1 Family attitudes

Family members influence the well-being of the child with a disability, but disability does not just affect the individual - it affects the whole family (Coleridge, 1993). Having a child with a disability in the family can influence the well-being of all family members (Beckman, 2002). The programme has acknowledged this to some degree, but it needs to be recognised more consciously that when you help the individual the family is helped, and that by working with the family the individual is helped (Lorenzo, 2003).

To achieve greater well-being there needs to be more collaboration with the informal and formal support systems of the families. The families live in interdependent structures. Although most children in this study live in nuclear families, the influence and importance of the extended family was emphasised by participants. The extended family can be very supportive, but those with negative attitudes contribute to stress and isolation of the families with disabled children. Negative attitudes emanate from beliefs about the cause of the disability and the 'why did it happen to me' question. It is not just about beliefs of the carers, but also of the extended family and the wider community. The carers seem well educated about the medical causes of their children's impairments, but ways should be explored to create awareness among the extended family members and opportunity to explore issues around guilt and blame.

How well a person with a disability will fare in a particular community seems to be predicted by three categories of social beliefs, namely: causality; valued and devalued attributes; and anticipated role (Groce, 1999). This refers to the manner in which the communities view the cause of the disability, which particular skills and activities are valued in that community (e.g. education), and what future role expectations the community has for a person with a particular impairment. People's expectations and demands for (or avoidance of and passivity about) rehabilitation services will be determined by these factors.

It is important to identify mechanisms of awareness-raising in the extended family. From the interviews it was clear that fathers and grandfathers play an important role in the lives of the children, but rarely take the child for exercises. It might be conducive to organise meetings where fathers and grandfathers are invited to share their views.

Hope is the main motivator for most of the carers. It is difficult for carers to let go of the image they had of the child's future before the child became disabled. They need to believe that there is a future, and that their child will be able to lead a quality life.

Parents may either over-estimate or under-estimate the child's abilities or prognosis. The ART programme needs to offer them a way to explore future opportunities realistically.

5.9.2 Need for support groups

The programme should identify and develop mechanisms to create space for carers to get support, and give them the opportunity to meet up and connect with carers in a similar situation. When carers are able to support each other, they can develop confidence in their ability to maintain health and manage illness (Boise *et al.*, 1996). This should be a comfortable space where people are able to talk privately without too much disturbance. The informal sector is not able to give enough support, and a support group might be a way for the carers to exchange experiences. It offers an opportunity for empathetic understanding as they are in groups with carers who have similar children. People experiencing similar situations are better able to understand and support each other.

According to Porter and McKenzie (2000), families' abilities to cope with stress are influenced by four issues, namely internal and external resources, support, their own goals for their children, and the local culture. The model was found also to be true for carers of children with disabilities in Uganda (Hartley *et al.*, 2005). The programme should look at ways to support carers in how to increase their abilities to cope. Awareness-raising, support groups and collaboration with informal and formal support systems could be away to do this.

5.9.3 Empowerment of the carers

A lot of the carers still feel insecure in their ability to assist in the development of their child. They feel that it requires more expert input. Adjusting to disability is a lifelong process. It is important that children and their carers start to feel confident in taking charge of their own lives. It should be explored how the programme could develop sessions with carers whereby they can be educated and empowered to feel more capable of bringing up their child. This should not just be done in the form of lectures, because carers should not feel they are being blamed, but ways should be found where carers can share their experiences in an empathic environment. The parents or carers need to be shown respect, solidarity and compassion. It would be beneficial if

CRWs were trained in simple counselling techniques to identify and appropriately deal with emotional troubles.

5.9.4 Individual development of carers of severely disabled children

Opportunities should be given for the carers of the more severely disabled children to develop themselves more in order to be able to continue looking after their disabled children. It has been said that human development is the foundation for social, political and economic development (Lorenzo, 2003; Burkey, 1993). Individual development can take place when the physical, emotional and spiritual needs of people have been met. Carers of the more severely disabled children should be supported in looking at ways in which they are able to meet those needs. They should understand that it is important to look after their own needs for them to be able to continue looking after their children.

5.9.5 Reducing environmental barriers

CBR programmes do not just work with the individual but also with the family and the community. Disability is to a large degree caused by societal barriers such as negative attitudes and institutional inaccessibility. The programme has tried to overcome some of the barriers in education, and has given education to the parents. It is important that the programme explores further how physical, attitudinal, social and institutional barriers in the community can be reduced - ideally together with the carers. The CBR programme so far is strong in medical rehabilitation, but can do more in the field of inclusion, equalisation of opportunities and poverty reduction.

A useful concept to explore is the balance theory developed by Albrecht and Devlieger (1999). They state that to have a good quality of life, a person needs to have a balance between body, mind and spirit, and needs to establish and maintain a harmonious set of relationships within his or her social context and external environment. Quality of life is a holistic concept, and goes beyond the activities of daily living and disease categories because it directs attention to the more complete social, psychological and spiritual being.

It has been shown that pain, isolation, and loneliness combined with environmental barriers can reduce quality of life. Disability programmes and development programmes are intersectoral in nature (Gueye, 1999). Lorenzo (2003), states that collaboration between different sectors should ensure the well-being of the person,

family members and community at large. The programme could develop collaborative partnerships with local institutions and projects to improve the quality of life of children with cerebral palsy and their carers.

5.10 Limitations of the study

This study could have been improved by using a multi-method approach. A more holistic view could have been obtained by evaluating the programme staff and community services such as the schools the children were attending. Due to time constraints, this has not been possible. This study was around one impairment, namely cerebral palsy. It evaluated the perceived change in quality of life of carers of children with cerebral palsy and their view about the change in the quality of life of their children. Only two of the children were interviewed personally. However, using a proxy approach in a study evaluating the change in quality of life is considered not valid as an indication of the person's own perception of their change in quality of life (Schalock *et al.*, 2002). There is especially a problem in the area of emotional experiences and personal preferences (Perry & Felce, 2002). An alternative evaluation approach suggested for children with severe disabilities is participatory observation within their own setting (Maes, Petry & Demuyne, 2003). To do this would have required a much longer time frame.

The study sample was small and it cannot be presumed that it is representative of all children with cerebral palsy and their carers in the programme. Another limitation was that although the interviewer did all interviews in Kiswahili, the transcribed interviews were then all translated into English. Some meaning gets lost in the translation. Also, some participants might have been reluctant to be critical, even though confidentiality was assured, due to fear of losing out on the programme's benefits.

5.11 Conclusion

This research study aimed to explore how the services of the ART CBR programme contributed to the self-perceived change in quality of life of disabled children and their carers participating in the programme. From the findings presented, it can be concluded that the most significant change achieved through the activities of the programme has been in the quality of life domain of physical well-being. For all the children in the study, as reported by their carers, there was an improvement in physical

functional ability; this varied according to the child. Some children had become very functional and achieved a great level of independence, while the group of severely multiple disabled children (group 1) remained very dependent.

CBR is an approach that uses and builds on the resources of the PWDs, their families and the community. To achieve improved quality of life, a programme needs to look at a child holistically, including the home situation and formal education. ART CBR programme offers a more institutionalised service, focusing on improving physical functioning and educational support. Overall, the carers interviewed in this study were satisfied with the changes in their children's physical well-being and the services provided to achieve this. However, to be able to address all domains of quality of life, the programme needs to offer a more integrated, needs-oriented service. Cerebral palsy impacts on more than physical function alone, and it involves a continuous process of adaptation of the children and their carers.

More should be done to integrate exercises within the daily activities of the child. Services such as communication exercises and provision of appropriate equipment should be improved. Problems such as social isolation, low self-esteem and carers' uncertain expectations of their children's abilities have not been sufficiently addressed. Opportunities should be offered to children to explore their feelings and to develop a positive self-image and identity. When children and carers start to refocus and adjust their priorities, they need emotional, spiritual and practical support.

The CBR programme should not just focus on the child but also on the family. Carers need to be supported to make better use of their social networks, and it is important that ways are found to create greater awareness among the extended family members. It would be beneficial if CRWs are trained in simple counselling techniques to identify and appropriately deal with emotional troubles. Support groups are a further option, as these could provide a forum for discussion and sharing of ideas about raising a child with disabilities, and facilitate the regaining of confidence.

Quality of life is dependent on finding a balance between body, mind and spirit in the self and maintaining a harmonious set of relationships within the person's social context and external environment (Albrecht & Devlieger, 1999).

For some of the children the programme has facilitated access to education. It is not quite clear to the carers of the more severely disabled children if their children will have an opportunity to go to school. Decreased access to education was mentioned in relation to reduced opportunities. Increasing access to quality education is perceived as improving well-being. Carers believe it increases access to work and economic

livelihood opportunities that increase the sense of control over life as well as access to social stable relationships.

Children with cerebral palsy and their carers know their needs, and through this evaluation have been able to express them. It is these needs rather than needs as assessed by professionals which must inform programme planning (Wirz & Thomas, 2002). It is hoped that the findings will facilitate the development of the CBR programme with the aim of achieving a greater quality of life.

The CBR programme has changed the quality of life of the children with cerebral palsy and their carers, especially in the domain of physical well-being and access to education. The programme should look at ways to offer support to improve the emotional, social and spiritual well-being of the children and their carers.

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APPENDIX I

Interview guide - Main questions to ask parents of children with disabilities

1. Can you tell me about the development of your child since he/she was born?

2. How has your child's life changed?

Alternative questions/probe:

- a. How has your family's life changed?
- b. If you think of your child now and compare him/her to before he/she got seen by CCBRT, is there any difference?
- c. Is there anything which has become easier or more difficult in your daily life since being seen by CCBRT?
- d. Has there been a change in the abilities of your child related to
 - Independence
 - Contribution into livelihood activities
 - Contribution towards income generation
 - Participation in family and community activities, e.g. religious, festive, leisure, etc.
 - Education (access, quality)
 - Parent: child-raising ability
- e. Has CCBRT made a difference to the treatment received in health services related to your disability? Probe: from local health services up to hospitals such as Muhimbili

3. Describe which services you (disabled person and his/her family) have found most useful?

Probe:

- a) Why did you found them useful?
- b) How has it benefited you or your family?

- c) Which other services would you like the organisation to provide?
- d) Which services could be improved?

4. Have your own priorities/wishes been addressed by the programme?

5. How do you see your own and/or your child's future?

Probe: Do you feel confident about the future? How do you see the life of your child 5 to 10 years from now?

Will he/she be able to run his/her own life, live independently, have a family?

What would need to happen to enhance your child's future?

6. What changes have you seen in the community?

How does the community look at your child's disability?

How does the community look at your family?

Probe: before CCBRT – now, neighbours/family/relatives

Beliefs, acceptance, segregation

7. Anything else you would like to contribute?

Main questions to ask people with disabilities

1. Can you tell me about your life before you became disabled, and how it has developed since then?

2. How has your life changed?

Alternative questions/probe:

- a. How has your family's life changed?
- b. If you think of yourself now and compare yourself with before you got seen by CCBRT, is there any difference?
- c. Is there anything which has become easier or more difficult in your daily life since being seen by CCBRT?
- d. Has there been a change in your abilities with regards to:
 - Independence
 - Contribution into livelihood activities
 - Contribution towards income generation
 - Participation in family and community activities, e.g. religious, festive, leisure, etc.
 - Education (access, quality)
 - Parent: child-raising ability
- e. Has CCBRT made a difference to the treatment received in health services related to your disability? Probe: from local health services up to hospitals such as Muhimbili

3. Describe which services you (disabled person and his/her family) have found most useful.

Probe:

- a) Why did you find them useful?
- b) How has it benefited you or your family?

- c) Which other services would you like the organisation to provide?
- d) Which services could be improved?

4. Have your own priorities/wishes been addressed by the programme?

5. How do you see your future?

Probe: Do you feel confident about the future?

How do you see yourself in 5 to 10 years' time?

Will you be able to run your own life, live independently, marry, have a family?

What would need to happen to enhance your future perspective?

6. What changes have you seen in the community due to the CCBRT work?

How does the community look at your disability?

How does the community look at your family?

Probe: before CCBRT – now, neighbours/family/relatives

Beliefs, acceptance, segregation

7. Anything else you would like to contribute?

Kiswahili: (Maswali ya mtunzi)

1. Unaweza kueleza kuhusu maendeleo ya mtoto wako tangu amezaliwa

2. Kuna mabadiliko gani katika maisha ya mtoto wako?

Sisitizo?

- Maisha ya familia yamebadilika kiviipi?
- Ukimwalia mtoto wako kabla na baada ya kupata huduma ya CCBRT sasa unaona tofauti gani?
- Kutokana na huduma za CCBRT, kuna mambo gani ambao yamekua rahisi au magumu katika maisha yako kama mzazi/mtunzi ya kila siku?
- Imechangiaje uwezo wa mtoto wako:
 - a) Kujitegemea
 - b) Kufanya shughuli ya kila siku?
 - c) Kupata kipato?
 - d) Kushirikisha katika shughuli za kifamilia na katika jamii k: kidini, sherehe, mapumziko
 - e) Elimu, kwenda shule
 - f) Wazazi: kulea mtoto mwenye ulemavu
- CCBRT imeleta mabadiliko yoyote ambayo yako tofauti na huduma ulizopata vituo vya afya kulingana na ulemavu ulionao (sisitizo zahanati mpaka Muhimbili?)

3. Umeapata huduma gani kutoka CCBRT?

Huduma gani umenona zina manufaa?

Sisitizo:

- a) Kutembelea nyumbani. Ungependa kutembelewa nyumbani marangapi?
- b) Imekuwezesha kukutana na walemavu/wazazi wengine?

Mnaona ni bora/mzuri kukutana na walemavu/wazazi wengine? Kwanini?

- c) Mazoezi ya shughuli ya kila siku, ya viungo, kuzumgumza, ushirikiano katik jamii
- d) Kurefa shuleni, zahanati/hospitalini, kanisani, nk.
- e) Kuanza mradi

4. CCBRT imeweza kukidhi matakwa/matarajio yako??

5. Unafikiri nini kuhusu maisha ya mtoto wako ya baadae?

Sisitizo: Unafikiri atafanya nini? atajitegemea? ataowa/olewa?

Unafikiri nini kuhusu maisha wako (kama mzazi) ya baadae?

Vitu gani vinahitajika kuboresha maisha yako au maisha ya mtoto wako ya badaaye?

6. Umeona mabadiliko gani katika jamii kwa kupitia CCBRT?

Jamii wanaonaje mlemavu wako/ mtoto wako?

Jamii wanaonaje familia yako?

Sisitizo: Kabla CCBRT – Baada ya, familia/ndugu//jirani,
Imani, kutenga, kukubalika

7. Kuna maoni mengine?

Maswali kwa mtu mwenye mlemavu:

1. Unaweza kueleza kuhusu maendeleo wako tangu amekuwa na ulemavu

2. Kuna mabadiliko gani katika maisha yako?

Sisitizo?

- Maisha ya familia yamebadilika kiviipi baada ya kupata huduma ya CCBRT
- Unaona tofauti gani kwenye uwezo yako kabla na baada ya kupata huduma ya CCBRT?
- Kutokana na huduma za CCBRT, kuna mambo gani ambao yamekua rahisi au magumu katika maisha yako ya kila siku?
- Imechangiaje uwezo wako:
 - a. Kujitegemea
 - b. Kufanya shughuli ya kila siku?
 - c. Kupata kipato?
 - d. Kushirikisha katika shughuli za kifamilia na katika jamii k: kidini, sherehe, mapumziko
 - e. Elimu, kwenda shule
 - f. Wazazi: kulea mtoto mwenye ulemavu
- a. CCBRT imeleta mabadiliko yoyote ambayo yako tofauti na huduma ulizopata vituo vya afya kulingana na ulemavu ulionao (sisitizo zahanati mpaka Muhimbili?)

3. Huduma gani umenona zina manufaa?

Sisitizo:

- a) Kutembelea nyumbani. Ungependa kutembelewa nyumbani marangapi?
- b) Imekuwezesha kukutana na walemavu/wazazi wengine?

Mnaona ni bora/mzuri kukutana na walemavu/wazazi wengine? Kwanini?

- c) Mazoezi ya shughuli ya kila siku, ya viungo, kuzumgumza, ushirikiano katika

jamii

d) Kurefa shuleni, zahanati/hospitalini, kanisani, nk.

e) Kuanza mradi

4. CCBRT imeweza kukidhi matakwa/matarajio yako??

5. Unafikiri nini kuhusu maisha yako ya baadae?

Sisitizo: Unafikiri utafanya nini? Utajitegemea? Utaowa/olewa?

Vitu gani vinahitajika kuboresha maisha yako/mtoto wako ya badaaye?

6. Umeona mabadiliko gani katika jamii kwa kupitia CCBRT?

Jamii wanaonaje mlemavu wako?

Jamii wanaonaje familia yako?

Sisitizo: Kabla CCBRT – Baada ya, familia/ndugu//jirani,

Imani, kutenga, kukubalika

7. Kuna maoni mengine?

APPENDIX II.

UNIVERSITY OF CAPE TOWN



Health Sciences Faculty
Research Ethics Committee
Room E53-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone (021) 406 6238 • Facsimile (021) 406 6413
e-mail: ethics@hsc.uct.ac.za

07 February 2006

REC REF: 023/2006

Ms J Van Der Veen
c/o Ms P Mayers
Health & rehabilitation Sciences

Dear Ms Van Der Veen

PROJECT TITLE: SELF-PERCEIVED CHANGE IN QUALITY OF LIFE CHILDREN WITH
CEREBRAL PALSY AND THEIR CARERS: PARTICIPANTS IN A COMMUNITY BASED
REHABILITATION PROGRAMME IN TANZANIA

Thank you for submitting your study to the Research Ethics Committee for review.

Date of meeting: 27 January 2006

Decision: It is a pleasure to inform you that the Ethics Committee has formally approved the above-mentioned study.

Please note: Open interview guide still to be developed – submit when completed.

Please quote the REC. REF in all your correspondence.

Yours sincerely

DR. M. BLOCKMAN
CHAIRPERSON, HSE HUMAN ETHICS

lemjedi

APPENDIX III. Informed consent introductory letter (English)

Judith van der Veen
CCBRT
PO Box 23310
Dar es Salaam

Date:

Re: Request for participation in the evaluation of the self-perceived change in quality of life of children with Cerebral Palsy and their carers

Dear Participant,

Thank you very much for your cooperation and willingness to participate in this evaluation project. This project will form part of a larger study on the impact of the CBR programme for persons with disabilities in this area. The project has been submitted to the Research Ethics Committee, Faculty of Health Sciences, University of Cape Town, for approval.

I am conducting this interview to know what you think about the work of the programme, and if it has made a difference in your or your child's quality of life. You have received the services from the programme now for some time and I think that you are therefore in a good position to give us some of your thoughts. I do not just want to hear all the good things but also about things which are not going so well, or suggestions that you have about the programme. The interview will last about 45 minutes and I request your permission to audiotape it.

We hope you make use of this opportunity to voice your opinions so it will contribute to the further development of the work of ART CBR and a better quality of life for people with disabilities. All information given to me will be treated with respect and kept in confidence. Your name will not be identified in any way, and your opinions will not influence in any way your involvement in the CBR programme. Should you wish to withdraw at any time, this will not impact on your rehabilitation programme.

I would appreciate it if you would sign the consent form below granting permission for me to use the information obtained in the research.

Judith van der Veen

Participant consent agreement

I agree to participate in the study to evaluate the self-perceived change in quality of life of people with disabilities and their carers.

This has been explained to me by the interviewer, Judith van der Veen.

I understand why the study is carried out and I am participating voluntarily.

I agree to be interviewed and grant permission for the interview to be taped. I grant permission that information obtained in the interview is used to write up the study. I understand that all personal information will be kept confidential and no identifying information will be used when writing up the research.

I understand that I am free to withdraw from the study at any time should I choose to do so.

Interviewee

Name:

Place

Date

Sign.....

Interviewer

Name

Organisation

Date

Sign.....

Informed consent introductory letter, Kiswahili

Judith Van der Veen
CCBRT
SLP 23310
Dar es Salaam

Date:

YAH: Maombi ya ushirikiano wenu katika stadi ya kutathmini maoni ya watoto na walezi kuhusu mabadiliko ya ubora wa maisha ya watoto wenye mtindio ya ubongo na walezi wao

Mshiriki Mpendwa

Asante sana kwa ushirikiano wako na moyo wa kutaka kushiriki katika hii stadi ya kutathmini. Mradi huu utakuwa moja kati ya stadi kubwa atika kuangalia matokeo ya husuma ya walemavu katika jamii (CBR) katika eneo hili. Ili kupitishwa, mradi umekabidhiwa kwa kamati ya research ethnics, Idara ya sayansi ya Afya na Chuo kikuu cha Cape town.

Nafanya usahili huu ili kupata mawazo yenu kuhusu kazi ya CBR na kama imeleta mabadiliko katika ubora wa maisha yako au ya mtoto wako. Mmekuwa mkipata huduma kutoka CBR kwa muda sasa na ninafikiri ni muda mwafaka kupata maoni kutoka kwenyu. Sitegemei kusikia mazuri tu ila pia mapungufu au maoni ambayo mnayo juu ya CBR. Usahili huu utachukuwa muda wa dakika 45 na naomba ruhsa ya kurekodi maongezi.

Tunatarajia kuwa mtatumia fursa hii kutoa maoni yenu ili yachangie kuendeleza kazi ya ART CBR na ubora wa maisha kwa watu wanaoishi na ulemavu. Habari zote zitaheshimiwa na kuwekwa siri. Jina lako halitatajwa na maoni yako hayatabadilisha kwa vyovyote ushirikiano wako na CBR. Ikiwa utajisikia kujiondoa wakati wowote kwenye usahili huu, basi haitabadilisha mpango wa huduma ya CBR kwako.

Nitashukuru iwapo utaweka sahihi yako ya kuniruhusu kutumia habari nitakazozipata kutokana na research.

Judith Van der Veen

Makubaliano ya Mhusika

Ninakubali kushiriki katika stadi ya kutathmini mabadiliko ya ubora wa maisha ya watu wenye ulemavu na walezi wao.

Nimeshaelezwa haya na msahili ambaye ni Judith Van der Veen.

Nimeelewa ni kwa nini usahilu huu unafanyika na ninakubali kujitolea kushiriki.

Ninakubali kuhojiwa na ninaruhusu mahojiano kurekodiwa. Ninaruhusu kuwa habari hizo zitumike katika uandalizi wa stadi.

Ninaelewa kuwa habari zote za kibinafsi zitawekwa siri na habari za kutambulisha hazitatumika wakati wa kuandika research hii.

Ninaelewa kuwa niko huru kujiuzulu katika Stadi iwapo nitaamuwa kufanya hivyo.

Msahili

Msahili

Jina

Jina

Mahali

Mahali

Tarehe

Tarehe

Sahih.....

Sahihi.....